Focus: Contemporary Challenges in Medicine and Research

Inside this Issue:
The Physician Payments Sunshine and the Health Care Reform Bill 2
Should you own your cells? 4
Do I really need to take that? A look into patient non-compliance 5
Altering the Definition of Life: The Ethics of Genetic Engineering and Synthetic Biology 6
The Theoretical Right to Health 7
To Flee From Memory 9
Addressing Excess Mortality from Cervical Cancer in Guatemala: Implementing VIA/Cryotherapy Screening 12
Disclosure of Unsought Information 15
Health as a Human Right: Common Humanity and Rights to Equal Opportunity 17
The Actuality of Autonomy: A Personal Reflection on Patients’ Rights 21

Letter from the Editor
Matthew De Niear ’11

The Ethical View is an annual publication released by the Medical Humanities program at Davidson College and is intended for a layperson audience. The goal of this publication, like the Medical Humanities program at Davidson, is to raise awareness about issues in medicine and their ethical ramifications.

The topic this year is “Contemporary Challenges in Medicine and Research,” which is also the topic of the 23rd Annual Frederick Womble Speas Symposium on April 14, 2010. The Speas Symposium offers an excellent opportunity for any interested Davidson College students to interact with individuals in the fields of medicine and bioethics.

The articles in this newsletter address several issues dealing with the patient-physician relationship, challenges facing healthcare systems both in the United States and abroad, and the moral and ethical dilemmas posed to medical researchers.

The patient-physician relationship and its associated obligations is a central theme running throughout this entire newsletter. The authors have chosen to focus on both the physician’s side of these issues, as well as the patient’s side by offering first hand accounts as physician interns and patients. These personal accounts offer a unique insight on this relationship from both perspectives.

The current issues facing the American healthcare reform process have been explored by authors from both theoretical and practical angles. Central to these articles is the question of whether healthcare is a right or privilege. Additionally, authors have chosen to explore issues facing healthcare systems outside the United States.

The current problems the medical research community is presently confronting has also featured in this issue. As scientific progress continues to achieve accomplishments at a faster face, the moral and ethical questions posed by these new discoveries and technology should prominently mark future ethical discussions. The authors have chosen to speculate on where some of these conversations may lead.

If you wish to respond to any article in this issue, please see the contact information on page 10.

About the Editor…
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On March 23, 2010, President Obama signed into law, the Patient Protection and Affordable Care Act (PPACA, H.R. 3590, now PL 111-148). Incorporated into the law (as Section 6002) is a version of the Physician Payments Sunshine Act (PPSA). In a nutshell, its provisions require drug and medical device manufacturers publicly to report gifts or payments made to individual physicians, physicians’ groups and teaching hospitals. It authorizes penalties up to $1,000,000 for non-compliance.

Why was the PPSA included in health care coverage reform?

The PPSA, coauthored by Senators Grassley (R-Iowa) and Koh (D-Wisconsin), initially was introduced in 2007. Grassley said: “Shedding light on industry payments to physicians would be good for the system. Transparency fosters accountability, and the public has a right to know about financial relationships.” Kohl said “Since we first introduced the bill, there has been a groundswell of support from every corner. Patients want to know that they can fully trust the relationship they have with their doctor.” The Pew Prescription Project, citing a study in the New England Journal of Medicine according to which more than 90 percent of physicians have some financial relationship with the pharmaceutical industry, opined that patients deserve to know if their doctors are receiving money from drug companies.

While affirming that many relationships between academic medicine and industry are necessary and beneficial, Pew expressed concern that these relationships create potential conflicts of interest, influence prescribing and drive up costs. Pew predicted that the PPSA provisions in the new health care reform law will better protect patients, restore trust in our health care system, enhance the safety of consumers, while in no way restricting business or limiting innovation.

PPSA supporters take pains to affirm that “many” of the relationships between medicine and industry are “necessary, beneficial.” However, the choice of words to title the legislation (“Sunshine”) and its comprehensive sweep suggests that virtually all of industry’s financial relationships with physicians should be presumed toxic for which, “Sunshine is the best disinfectant.”

Does the Law limit gifts and payments?

No, the Law requires reporting and public disclosure of information. It does not limit gifts or payments. Thus the law reporting and disclosure did not go far enough for critics who favored banning outright physicians’ relationships with industry, especially any financial relationships.

Who must report and How often?

“Covered entities” and “applicable manufacturers” must do the reporting. Covered entities Include any group purchasing organization that purchases, arranges for or negotiate the purchase of a covered drug, device, biological, or medical supply which operates in the United States and its territories. Applicable manufacturer includes all U.S. manufacturers of drugs, devices, biologics, and medical supplies covered under Medicare, Medicaid, or SCHIP. Reports of payments made to “covered recipients” must be made annually to the Department of Health and Human Services (HHS). The start date for recording is January 1, 2012. Start date for reporting is March 31, 2013. Publication of reports begins on September 30, 2013 and June 30 in future years.

HHS must post the information on an easily searchable public website enabling the downloading of the data. The Secretary of Health and Human Services is further required to submit annual summary reports to Congress, as well as annual reports to each state. Also required are reports on self-referral for imaging services. A referring physician must inform the patient in writing at the time of the referral that the patient may obtain the referral services from alternative providers and must provide a list of service providers in the area in which the patient resides.

Who is a 'Covered Recipient'?

Covered recipients include physicians, physicians’ group practices and teaching hospitals.

What counts as a reportable payment, gift or transfer of value?

The Law requires disclosure of payments whether in cash or in-kind to all covered recipients specifically to include: compensation; food, entertainment or gifts; travel; consulting fees; honoraria; research funding or grants; direct compensation for serving as faculty or a speaker for a medical education program; speaking fees; education or conference funding; stocks or stock options; ownership or investment interest; royalties or licenses; charitable contributions made in the name of a covered recipient; and any other transfer of value as determined by the HHS Secretary.

The Pharmaceutical Marketing Research Group (PMRG), a trade association representing pharmaceutical and medical device manufacturers and their consultants, scored a significant victory by having excluded from the Law’s reporting requirements, payments made to...
Delayed reporting of payments for research or product development

Payments related to clinical trials or product development agreements for new products are allowed a publication delay of four years or until product approval, whichever comes first. Publicizing of product development agreements for “new applications” of existing technologies may also be delayed. Product development agreements are not defined.

What else will be disclosed?

Manufacturers and group purchasing organizations must disclose physician ownership or investment interest.

How does the Law affect existing state laws?

States are prohibited from collecting the same information required to be reported PPSA section. States may collect data not captured or excluded from reporting (with the exception of de minimis and threshold limits). States may also collect data for public health purposes or on legal proceedings.

What are the penalties for non-compliance?

For each failure to report, fines of up to $10,000 will be applied, not to exceed $150,000 annually. For each knowing failure to report, fines of up to $100,000 will be applied, not to exceed $1,000,000 annually.

Implications:

The Pharmaceutical Marketing Research Group argued that imposing PPSA’s reporting requirements for payments made to physicians for completing market surveys would tend to deter physician participating in socially useful research. This argument bears further consideration. It assumes, plausibly, that physicians’ willingness to participate in survey research would be sensitive to “disclosure.” In other words, Sunshine would have tended marginally to increase market survey participation costs to physicians. Depending on how physicians would have regarded this cost, a higher payment to secure their continued willingness to participate would be required. How much higher would depend on how physicians price their time plus compensation for the loss of anonymity.

The deterrent effects of Sunshine apply more generally to the question whether PPSA will adversely affect the extent of socially useful cooperation between physicians and industry and whether it will have a chilling effect on innovation. Predictably, PPSA’s supporters touted the benefits of the Law. Pew, for example, foresaw only benefit for enacting it and no risks or costs for doing so. To my knowledge, no credible cost/benefit estimate of PPSA has been done. No “Sunset” provision applies. No one can be confident about the Law’s effects. We can hope that collecting, reporting, disclosing and maintaining the capacity to manage such a large volume of data will be worthwhile, that it will be net-beneficial despite the costs, some predictable, many not. The costs will not be born equally. Larger, more powerful companies will more easily bear them, smaller, less powerful companies less easily. The information costs for those who study the financial relationships between industry and medicine will go down.

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Imagine decades from now discovering that biological material (tissue) taken from one of your relatives has contributed to some of the most important recent medical research—but you had no idea. This might sounds like fiction, but, as the family of Henrietta Lacks learned, it could be closer to fact. Rebecca Skloot chronicles this remarkable story in her recent book, “The Immortal Life of Henrietta Lacks.”

Lacks, a poor African-American tobacco farmer, born in 1920 has played a larger role in the advance of modern medicine than either she or her family ever could have imagined. She died in 1951 from cervical cancer, but not before scientists removed a piece of her tumor for research purposes without her knowledge. Scientists soon discovered that the cancerous cells were especially resilient, appearing to multiply indefinitely in the presence of just a few nutrients. These so-called “immortal” cells gave researchers an unlimited supply of raw material and a chance to continue experimentation on them for as long as they wanted. Over the next decades, Henrietta Lacks’ (HeLa) cells played an integral part in scientific research. HeLa cells proved to be a cheap and easy way to test the polio vaccine, helped to develop techniques later used to create Dolly the cloned sheep, and have even gone to space to examine the effects of zero gravity on human tissue. Researchers also realized that HeLa cells could become profitable. The biotechnology company Microbiological Associates got its start selling the cells. Skloot reports in her book that there are now more than 17,000 US patents involving HeLa cells in one way or another, and bi-products now sell for as much as $10,000 per vial, making HeLa one of the most popular cells lines in the world.

Despite the scientific and commercial success of HeLa’s cells and DNA, Lacks’ family was completely unaware until the 1970s. How was her family supposed to feel upon this remarkable discovery? Pride and joy at the fact that their family member had helped save thousands of lives? Anger and confusion as to why they were uninformed of the countless uses of their relative’s cells? A desire to reap some of the financial benefits of research? Marginal economic benefits could have had a profound effect on the lives of Lacks’ family members; Skloot reports that some of Lacks’ descendants do not even have health insurance.

The limits of financial compensation was legitimated in a 1990 California Supreme Court decision stating that cells are considered “biological waste” once they leave the body. The court ruled that leukemia patient, John Moore, had no right to share in the profits realized from the commercialization of his discarded body parts (tissue). Just as in the case with Henrietta Lacks, not only can this mean no benefit to the individuals who contributed body tissue to research, but it can also result in profit for researchers who choose to patent valuable genetic information. There are currently between 3,000 and 5,000 such patents on human genes in the United States and 47,000 on inventions involving genetic material.

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Perhaps nowhere has the controversy over gene patents played out more prominently than in the case of seven patents on BRCA1 and BRCA2 genes held jointly by Myriad Genetics and the University of Utah. These genes have been linked to most of the inherited cases of breast cancer, and may play a role in ovarian and other cancers. In May 2009, a coalition of civil rights, research, and women’s rights groups filed a claim against Myriad, alleging that the patents—which gives Myriad exclusive rights to conduct diagnostic tests on the genes—stifles innovation by discouraging other researchers from looking at the genes. On March 29, a federal judge struck down Myriad’s patents on the two genes, ruling that the patents were “improperly granted” because they involved a “law of nature.” John Ball, executive vice president of the American Society for Clinical Pathology, hailed the decision as “good for patients and patient care…science and scientists.” This decision, if it survives appeal, has the potential to have huge impacts on keeping scientific research open and free from “exclusive rights,” thus allowing greater proliferation of valuable information.

Recent research helps to substantiate such a claim. Robert Cook-Deegan of Duke University, who conducted a review of genetic tests for ten medical conditions, found that the exclusive rights holder was the last one on the market and used its power to shut down smaller labs that had developed their own tests. Cook-Deegan and colleagues more recently found that one of Myriad’s patent claims on BRCA1 is “surprisingly broad, and if enforced would have substantial implications for medical practice and scientific research.” Such findings raise important questions about research on human biological tissue.

How do we ensure that patients willfully and fully consent to the use of their body tissue? If truly informed consent has occurred, do patients have a right to know where their “disposed” body tissue ends up and how it is ultimately used? Would patients object to donate body tissue in the first place if they were disposed of this information? Should patients remain behind a veil of ignorance...
Do I really need to take that? A look into patient non-compliance
Matt Fore, Davidson College ‘11

You are sick and want to get better, right? Well here is what I suggest. Go to the doctor, obtain a diagnosis, get the medication he or she prescribes, and take your pills as instructed. Following the “doctor’s orders” seems like a simple concept, yet one of the most common complaints I’ve heard from doctors that I have shadowed or talked to is that people simply are not taking their medications. Doctors hear complaints like “I don’t like taking pills,” or “I felt fine after a few weeks so I stopped” all the time. With each excuse, the doctor resists the urge to roll his or her eyes, as if to say, “Well, you don’t really have a choice. Your body needs these medications to stay healthy.” A few doctors have even told me—after we had left the examination room of course—that they really just want to yell at these patients in hopes of getting some sense into them. They were frustrated to say the least.

The problem, patient non-compliance, may not always be the patient’s attitude toward medications, but simply a lack of patient understanding and education regarding medical treatments. The public at large generally views doctors as “body mechanics” that can fix something with a magical touch, and then are paid for the services they render. Slowly but surely this perception of a quick fix is changing. People are now realizing that some conditions, especially conditions like high blood pressure or diabetes, are chronic and require life-long attention. Patient non-compliance also place added costs on the healthcare system at a time in which all unnecessary burdens are attempting to be eliminated. The Associated Press reported that in 2007 millions of U.S. residents were not taking their prescriptions drugs properly or at all, which could cost as much as $177 billion in medical bills and lost productivity per year. The report also found that this is associated with up to 40% nursing home admissions.1

The FDA acknowledges problems that lead to patient non-compliance including the inability to pay for medications, the difficulty involved with keeping up with multiple medications and complex dosing schedules, and confusion on when and how to take the medications. The FDA offers several ways to alleviate these dilemmas to patients like constantly communicating with your physician, especially with any questions or concerns you have about dosing or costs, and keeping medications in a noticeable location and using daily dosing containers.2 Dr. James Kay, a cardiologist that I shadow at Presbyterian Hospital, definitely agrees with keeping the lines of communication open with your healthcare professional, although he also believes further education of the public is necessary. Dr. Kay works at a university hospital, where he says he generally sees lower income patients. He says that aside from not being able to afford medication, the biggest problem he faces is their understanding of the importance of medication. For each patient Dr. Kay says he, “make(s) an attempt to inform them [the patients] what I'm treating with each medication, what the risks are of not treating the diseases, and what side effects they can possibly expect. For many patients, a few minutes in clinic going over those issues, as well as selecting generic medications that are available for as little as $4 per month, goes a long way to improving compliance.” Dr. Kay’s philosophy is that simple education in this matter would go a long way in improving their overall health, and even help keep their future healthcare costs down.

Professional medical societies have also weighed in on the problem of patient non-compliance. The American Heart Association (AHA) has some educational tools and reminders on their website, which advocates for some similar things that Dr. Kay does. They say that the patient should not insist on which drugs the physician should prescribe, and to talk to the doctor about any side effects the patient may experience. In addition, the AHA insists that you should not run out of pills for even one day as this may increase your risk for heart attack or stroke, and to tell your physician about all your other over-the-counter and prescription drugs. The AHA also makes the patient aware that they should expect to treat high blood pressure for life, which makes it all the more important to take your medication as prescribed.3

With all the frustration that accompanies some patients, doctors must understand that patients should be fully educated about their treatments and how it is the patient’s responsibility for their health, not the physician’s. Several organizations strongly encourage more communication between healthcare providers and their patients, a vital step in raising awareness of the importance of taking your medications properly. Without proper information and understanding, patient confusion builds, which often leads to frustration and possibly even stopping the intake of medication altogether. This detrimental outcome is undesirable for both the patient and the physician. It should be a part of both the physician’s and patient’s philosophies for successful treatment.

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1 http://www.medicalnewstoday.com/articles/78397.php
2 http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm164616.htm
3 http://www.americanheart.org/presenter.jhtml?identifier=2109

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Altering the Definition of Life: The Ethics of Genetic Engineering and Synthetic Biology
Matt Lotz, Davidson College ’11

Recent history has produced exciting research advances in the overlapping fields of molecular biology and genetics. Today, we now have legitimate and viable research prospects in synthetic and genetically altered life. This recombinant DNA (rDNA) research has produced realities like gene therapy, genetically modified crops, and human-made genomes, which were once merely science fiction-esque. These advances have spawned allegations that scientists are “playing God” in their altering of the genetic make-up of organisms. This is likely a stretch of the truth since scientists are working within the framework of life and preexisting reality— they are not producing something from nothing. Yet there is not the slightest doubt that these advances have elevated the ability of humankind to control their surroundings and the life within them. As research produces more and more possibilities, scientists are going to need to define ethical guidelines backed by legislation that evolves with the discoveries they’ve made. Without such guidelines, some scientists will certainly follow their insatiable humanly thirst for knowledge, which could lead to irreversible problems.

Some of the most exciting, while simultaneously controversial, research is being conducted by Craig Venter and the J. Craig Venter Institute. Venter, a leader and proponent of the shotgun method of genome sequencing within the private sector during the early years of the Human Genome Project, has now turned his attention to building the first fully synthetic genome and transforming it (i.e. putting the genome) into bacteria. First, researchers at the Venter Institute used Mycoplasma genitalium, the smallest known free-living bacterium with a genome of 517 genes, to determine the minimal genome needed to sustain life. They found the bacterium only needed a core set of 265 to 350 genes to sustain life. In 2008, they synthesized the M. genitalium genome from scratch – at nearly 600,000 base pairs, this is the largest synthesized genome to date. Currently, Venter and his company Synthetic Genomics are pursuing novel uses of these discoveries by seeking to engineer bacterial genomes that are able to produce biofuels from lignocellulosic biomass.

The potential of genetic engineering and synthetic biology is astounding. Companies outside of Synthetic Genomics (e.g. Solazyme, Gevo) are also in search of an economically viable bacterial solution to creating usable biofuels from excess agricultural biomass or algae. In addition, rDNA technology holds promising potential in pharmaceuticals—to produce drugs cheaply, and fight disease autonomously with synthetic bacteria or viruses, or through gene therapy. In one case, Jay Keasling of UC Berkley has engineered yeast to produce artemisinic acid, a precursor to the anti-malarial drug artemisinin, which is a highly effective in its action, but at present a rare and expensive treatment. rDNA advances will revolutionize drug production and the subsequent effects of these changes will likely increase drug access to less affluent countries.

Despite the potential of rDNA and genetic engineering to do unprecedented levels of good, there is also room for these discoveries to lead to disaster – both intentional and unintentional. For instance, the poliovirus was synthesized by researchers at SUNY Stony Brook in 2002. As the first synthesis of a virus, this was a landmark feat for synthetic biology; however, it brought some negative issues that could result from such a development into focus. The genetic sequence for poliovirus and other pathogens are freely available online – thus, malevolent factions could use this information to spread disease to many people. In another scenario, a genetically engineered organism could inadvertently escape the laboratory area and impact the outside world. Eventually it is likely these organisms will likely interact with the outside world. What are the implications of this in the short- and long-term? Researchers could be harmed in their pursuit of great advances. These issues of fallout from new technologies and discoveries will need to be carefully considered on a case-by-case basis as researchers push the limits of understanding.

There are also even more fundamental ethical questions concerning the reworking of the very building blocks of life— are we intruding on the sanctity of life? These concerns need to be addressed adequately as we explore new levels of science. To examine the latter of these two issues, one must first define the meaning and value of life and our interaction with it. Clearly, these are no simple tasks. There are a wide array of opinions which stem from religion and philosophy regarding the sanctity of life. These tenets must be respected as science moves forward into the unknown. Likewise, non-scientists and those who disagree with genetic engineering need to recognize the new understanding of life and its new potentials. Therefore, a new and mutual boundary must be formed – what can and can’t we do with life?

(Continued on page 14)
The Theoretical Right to Health
Molly Merrill, Davidson College ‘10

The World Health Organization defines health as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (WHO, 1948).” The Universal Declaration of Rights mandates that “everyone has the right to a standard of living adequate for the health and well-being of himself.” When these definitions are taken together, people are guaranteed more than a lack of government interference in the attainment of health; but also help in guaranteeing a standard of living to encourage health. The issue of whose responsibility and whether there is a right to health is a hotly debated topic. If health is viewed as merely a goal to be reached for social justice reasons, a moral imperative to ensure fundamental access to healthcare and health care determinants is noticeably absent. A theoretical, positive right to health exists, recognizing the inability of every government to meet the universal standard due to a lack of resources.

A right can be defined as “entitlements both to do, have omit, or be something and to demand that others act or refrain from acting in certain ways. These entitlements, or claims, impose correlative duties on others in society.” Rights vary based on the culture but a set of rights mandatory to maintain human dignity, human rights, exist. Human rights are “that set of rights or entitlements that all people in the world have regardless of where they live.” Human rights consist of a baseline of political, civil, economic, and social rights that are necessary in the name of civilization and are given because one is a human. The major classification of human rights can be broken down into positive rights and negative rights. A positive human right is a right that allows a person to impose an obligation on another party. Negative rights are those rights given that require no positive action from the government or society. An individual can have a negative right without a positive right being implied or mandated by the government or society. However, debate exists to what degree a negative right can exist without a positive right to guarantee the freedom. A gamut of opinions exists discussing the relationship between positive and negative rights and the extent positive rights should be established to enforce a negative right. Classic liberal thought generally focuses on negative rights and issues of government restraint with little emphasis on protections by positive rights. Alison Barnes best describes an issue with classical liberal logic in “The Various Human Rights in Healthcare” as, “the right exists regardless of whether positive law has given it expression; a human right not recognized by positive law is a failure of the law, not an absence of the right.” Thus, a negative right not enforced by a positive right may result in the absence of a human right being satisfied. Thus, a classic liberal view of the right to health will not offer protection to the right to health if everyone cannot reach the right to health by merely negative rights.

The right to health is a complex right that encompasses many human rights. In the international health context, the right to health includes the right to healthcare as well as the right to other health determinants, such as the right to clean water or the right to nourishment. The UN Committee on Economic, Social, and Cultural rights defined the right to health as both the right to health care and health determinants. Health determinants are those issues necessary to be met for a person to have control over their personal health. Health determinants include rights such as adequate sanitation and safe workplaces. Some argument exists that the right to health is the incorrect term and no such right could possibly exist. The term “right to health” has an implication of the right to be free from illness, which may not be possible due to pre-existing conditions as well as the varying definitions of health depending on the person and their cultural context. For example, in South America, the disease spirochetosis is so commonplace, a person with this skin disease may still be considered healthy. Yet, in order for health to be a human right, it needs to have the same application for all humans and transcend all cultures. Even the issue as seemingly simple as whether the right to healthcare is a positive or negative right can be shaped by its cultural context.

The issue of health should be examined through the issue of rights as opposed to the other common frameworks given of humanitarian, utilitarian, or social justice. When considered through the veil of human rights, the means exist to hold governments accountable to their citizens. A large amount of responsibility is placed on the government and people can exert an element of control on their lives. When there is a standard dictated by human rights, people can compare themselves to the standard to both get angry with and demand more help from their government or have a goal that they can aspire to meet. Health through the lens of human rights mandates a minimum level of health resources people are entitled to on the basis of their humanity. This method allows for people or nations to be held responsible to guarantee a basic standard of health. This approach views humans and human dignity as an end unto itself. One problem sited by looking at health through the lens of rights is the issue of implementation where communities have varying levels of abilities to meet the goals. However, this issue can be remedied if tempered with equity, whereby resources flow from resource rich areas to those that need help. Already, there is a need to define health as more of a pan-national goal, the globalization of the world and the world’s economy means the movement of people around the world and a pandemic in Africa can quickly spread to an epidemic in the United States. If health is not defined as a right then health of all people is reliant on the goodwill of countries that have money acting in a humanitarian or social justice manner.

(Continued on page 8)
Although the word “health” is nowhere in the Constitution, a human right to health still exists. Article I in the Constitution, which allows the government to make laws that “provide for the general health care,” is typically cited to validate the right to health. This tenuous constitutional basis for the right to health is reflected in the limited amount of positive protections made available for this right. In the United States, the classical liberal idea, is for “individual agency” where health comes about as a reward for “personal achievement.” This thought is typified in the relatively greater amount of public support that Medicare has over Medicaid. More recently, Obama’s focus on a plan for national health care was not justified based on every person’s right to health care. Instead, it was justified as being able to keep the cost of health care down. In this logic, if people are chronically not attaining their right to health, their negative rights are not being fulfilled enough, e.g. their right to be free from discrimination. Even the classic definitions of liberal, however, argue that some level of basic protections should be made available to people through the protection of negative rights in the form of positive protections.

There is also an egalitarian definition to the right to health that recognizes that health is a product of social conditions. The egalitarian approach accepts that such circumstances as the Matthew Effect do play a role. Health cannot solely be determined by the individual but as a product of their social environment. The egalitarian view recognizes that people need a baseline of rights to live up to their potential of rights that the liberals want to guaranteed, namely to compete in the market. This approach does not demand for the right to health in the WHO’s definition of health but rather as “a minimum necessary to allow for a dignified life.” Scientific data supports the egalitarian view of the right to health, for example the case of Coronary Heart Disease. All of the known biomedical predictors for Coronary Heart Disease make up approximately 50% of the reasons that people have contracted CHD. Further, those that place health in a more traditional liberal lens fail to acknowledge that rights do not always fit cleanly into either positive or negative rights. Although liberals often cite a lack of consensus as a reason, the right to health cannot be attained, they do in fact agree that some positive rights are necessary in certain circumstances, such as the active protection against harm. It is unfair to assume that no same consensus can be reached when the government is deciding its responsibility for its citizen’s health. Further, just because the United States is notoriously behind on social justice reforms and other issues that would affect both health care and health determinants does not mean the rest of the world is. Many constitutions and treaties acknowledge the right to health, most famously being the Universal Declaration of Rights.

As a positive human right to health exists, some body is responsible for upholding and actively protecting the right. The issue comes up as to whom to hold responsible to protect the right associated with health if it is not being met. Some entity needs to be held responsible to ensure the right to health for global funding is not guaranteed to reach its specified target. Furthermore, as Chapman notes, “There is a vast difference between rhetorical affirmations of acceptance of various rights and their implementation (p. 108)”. The right to health can be affirmed as a human right without having the adequate resources to ensure the right to everybody. There is recognition that it is impossible for the world to meet the WHO’s definition of what health is. Even within the United States, 45 million people do not have access to health insurance and another 50 million do not have adequate insurance (Editorial). It is recognized that 15% of the government expenditure of 29 countries would have to be devoted to solely health-related Millennium Development goals for them to be attained. These MDGs do not even address the issue of poverty. However, poverty is an important determinant to the right to health. Poverty increases stigmatization, which in turn leads to a lower health status. Over 2 billion people live on less than $2 a day so bringing up their health determinants clearly needs an influx of dollars from richer countries. A global recognition of rights could cause a body to be established to make sure wealth is redistributed so everyone can meet their basic human rights. In this method the practice of globalization could bring about the reduction of global inequity to the right to health instead of the traditional role of increasing inequities.

Barring the possibility of raising everyone to the highest standard possible, the issue becomes reaching a consensus of what all the governments are responsible for to meet its citizens’ human rights. The lack of resources to make the right available to everyone does not make health any less of a human right. The issue of not enough funding should not prevent a government from trying to reach a base level of rights. Evans describes the responsibility established by the right to health the best, (Continued from page 7)
The article “The Ethics of Erasing a Bad Memory” describes a clear violation of the ethical principles of respect for patient self-determination and respect for a patient’s bodily integrity. Dr. Haig and the anesthesiologist violated these principles when their patient, Ellen, was sedated without her consent and consequently deprived of her memories within the ten minutes prior to her being sedated. While the anesthesiologist may have perceived his action as benevolent care towards the patient, such paternalistic action cannot be justified because the treatment occurred without Ellen’s consent and therefore violated the aforementioned principles. Additionally, the failure of Dr. Haig and the anesthesiologist to disclose to Ellen the occurrence of her sedation and subsequent memory loss further compromises the trust essential to the fiduciary nature of the physician-patient relationship. While on the surface this case seems to evoke issues of respect for persons in the context of informed consent and the physician-patient relationship, a complete ethical analysis of this case also requires a more extensive exploration that implicates of this case have within the greater ethical framework and public policy. Yet despite any conclusions that may be construed from this case’s implications, Dr. Haig and the anesthesiologist’s conduct in this case remains unethical because of their failure to respect the principles of informed consent and to protect the physician-patient relationship.

Respect for patient self-determination and respect for a patient’s bodily integrity are two underlying ethical goals of informed consent. Informed consent at its fullest allows patients to most completely exercise their own autonomy. Though the legal standards of what constitutes informed consent may vary on a state by state basis, in most complete terms informed consent allows a competent patient to make an informed decision after he/she understands the nature of a treatment, the risks and benefits the treatment carries, what alternative treatments may be available, or anything else a reasonable person may wish to know. When treatment is given without proper or any informed consent, the patient’s right to make his/her own decisions has been disregarded and an unauthorized handling of the patient’s body occurs. Physicians often believe they know what course of action is best for their patient because of their usually superior medical training and social station. This paternalistic medicine may aim to ultimately “better” the welfare of a patient, yet it does so at the expense of regarding the patient as a reasonable and capable decision maker with certain unalienable rights.

The case of Schloendorff v. The Society of the New York Hospital is an example of paternalistic reasoning on the part of a physician leading to the application of unauthorized treatment. In this case, the physician’s decision to remove a tumor, despite only being authorized to biopsy the mass, violated Ms. Schloendorff’s right to self-determination as to her course of treatment. While the physician reasoned that he was acting in the best interest of his patient by avoiding the risks of conducting a second surgery and anesthetization, the court rebuked this notion by affirming that operation without patient consent is trespass. The court’s assertion that “every human being of adult years and sound mind has a right to determine what shall be done with his own body” set an early twentieth century precedent for the necessity to obtain patient consent prior to treatment in spite of what the physician himself thinks is in the patient’s best interest.

In the case described by Dr. Haig, the anesthesiologist presumed that sedating Ellen and erasing the memory of her diagnosis was the best course of action for her wellbeing. The benefits of sedating Ellen and erasing the traumatic memory of the sudden cancer diagnosis were evident in the opinion of Dr. Haig, but could these apparent benefits justify the anesthesiologist’s decision? Like the physician in the case of Schloendorff v. S.N.Y.H., the anesthesiologist committed a trespass against Ellen by giving her unauthorized treatment. The troubling implication of the parallel between these cases is that paternalistic thinking is still present within physician decision making almost ninety years after the Schloendorff case was decided. The problem with paternalistic thinking is that not that it advocates a particular course of action that the doctor thinks is best, but rather that it exerts the physician’s will over the competent patient. To some extent, the physician may feel compelled to advocate for a certain course of action against a patient’s wishes for fear of charges of a civil suit if what the patient wants produces a negative outcome. Yet such fears do not seem to be well founded as the law has affirmed the right for a competent adult to refuse even life saving treatment and in doing so forfeit the ability to seek damages. This scenario was demonstrated in

(Continued on page 10)
The fiduciary duty given to physicians is in keeping with the general ethical principle of respect for persons presented in the goals of informed consent. The physician-patient relationship is a fiduciary relationship by which a patient entrusts the care of his/her body to be treated in good faith by the physician. In Ellen's case, she entrusted her body to the care of Dr. Haig by consenting to him performing a biopsy of the lump in her shoulder under local anesthesia. Although Ellen did consent to Dr. Haig's request that an anesthesiologist be present during the procedure, Ellen assumed that she would only be fully sedated if she was in severe pain or an unusual complication arose from the biopsy. By never informing Ellen she was sedated and that her collective memory was deprived of ten minutes of her conscious life, Dr. Haig and the anesthesiologist breached their fiduciary duty.

One aspect of the fiduciary relationship is that the party, in this case the patient, who entrusts his/her body to the physician is in weaker position of power and/or knowledge. The element that forms the foundation for this relationship to occur is the patient's trust in the physician. In failing to both adhere to the guidelines of the consent and failing to disclose the departure from this agreement to Ellen, the physicians broke the trust between the physician and patient. It is important for the medical community as a whole to protect the physician-patient relationship because it is necessary that patients trust their physicians and feel comfortable allowing physicians to actively treat their body. When such trust is broken, such as in this case, it would be difficult to expect the patient to trust any suggestions made by the physician. One could argue that the failure of Dr. Haig and the anesthesiologist to disclose to Ellen that she was sedated provided Ellen with a false sense of trust between her and Dr. Haig. Had Ellen known of her sedation, her relationship with Dr. Haig would have fundamentally changed, even possibly to the point at which Ellen would have left the care of Dr. Haig. These implications demonstrate the necessity within the medical profession to avoid breaching fiduciary duty.

As the title of the article seems to imply, the case presented by Dr. Haig raises ethical questions of a broader nature than simply the moral nature of Dr. Haig and the anesthesiologist's actions. One reading this article must ponder whether the act of erasing a memory is ethical, even if the memory is erased with consent of the patient. Research in the treatment of posttraumatic stress disorder (PTSD) seem to suggest that situations may exist in which individuals would willingly consent to the "erasure" of the memories.

PTSD is a psychophysiological condition that stems from the exposure to a traumatic event or situation of extreme stress. Approximately 5.2 million adults in the United States are believed to be suffering from PTSD and their treatment costs the government four billion dollars annually. One of the contributing factors that aids the development of PTSD in victims of a traumatic experience is a robust noradrenergic response leading to increased reconsolidation (the process by which short-term memories are encoded into long-term memory). A recent study suggested that the administration of the beta-adrenergic receptor antagonist (more commonly known as a beta-blocker) propranolol blocks noradrenergic transmission in the lateral amygdala, a neural substrate of the brain where the process of memory reconsolidation is believed to occur. The effect of this process decreases the chance that symptoms of PTSD will occur because the memories of the traumatic experience are "erased." The ability of propranolol to erase memories and the potential desire of those victims of

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tria who wish to prevent PTSD has prompted the President’s Council on Bioethics and many bioethicists to speculate the implications and ethicality of such treatment 6.

At the most abstract level, bioethicists have questioned how the erasure of traumatic memories will shape one’s moral and ethical beliefs if he or she does not recall such a traumatic experience. Our memories provide us with information not only from the past, but also with reference to the present and the future. Past memories may include both our semantic knowledge of facts and our episodic knowledge of where we have been and what we have done. Intrinsically, these past memories shape our “person” in the present and the future because they remind us of how we have thought about things in the past. William Kabasenche and others express concern that such erasure of memories would deprive people of their ability to feel emotion in response to traumatic events and thereby obscure their moral identity 4. While these concerns do seem valid in the context of extensive memory erasure, they do not seem to the most immediate concern of bioethicists.

The erasure of memories does raise more immediate concerns in the context of informed consent. Ethicists demonstrate some concern that the competency of those people who have recently suffered a traumatic event cannot be assured 5. This objection seems reasonable, unless we view the erasure of the memory as a psychological treatment, in which case the treatment is no more serious than consent to a prescription of SSRI’s (Selective Serotonin Reuptake Inhibitors) 2. Yet not all ethicists view the prescribing of memory erasing pills to be the same as prescribing Prozac. Evelyn Tenenbaum conjectures that the erasure of traumatic memories would have societal impacts that must be disclosed to patients as part of the informed consent process 6. Tenebaum argues that the impacts memory erasure could have to one’s duty to society, such a serving as a credible witness to a crime or having a recollection of past atrocities, must be conveyed to an individual before they consent to have their memory of such events 6.

The prospect of one’s ability to testify as a witness following the erasure of memory poses some interesting legal questions. Adam Kolber suggests that those who received treatment to erase memories of a traumatic event of a criminal nature would no longer be credible witnesses. Under this hypothesis, these individuals would fail to fulfill their duty to society by failing to testify 5. The government has shown interest in preserving the life and capabilities of a witness to testify as In Re: Mattie Brown, whereupon the State of Mississippi requested court order to transfuse blood against Ms. Brown’s wishes; however, this order was ultimately not granted 3. The reluctance of the court to continue to grant such an invasive order suggests the government would not be able to legally prevent a witness from choosing to erase his/her memory. To describe the legal implications of a case of a person whose memory was erased without consent, Kolber cites the case of the erasure of Ellen’s memory. He argues such an act was unethical because anesthesiologist, by erasing Ellen’s memory, erased evidence of his violation of Ellen’s consent that could have been used in a civil suit against him 5. Such speculative arguments suggest that legal, medical, and social policies would have to be adapted if memory erasing drugs were adopted as a form of medical treatment.

In the case of Ellen, Dr. Haig and the anesthesiologist’s actions were unethical because they failed to respect their patient’s person by acting without her consent. Equally, they failed to uphold their fiduciary duties to their patient by not disclosing her sedation and subsequent memory loss to her. The concept of erasing one’s memory for therapeutic treatment raises a score of speculative ethical issues. Through memory, one draws on the past experiences and thoughts that have been collected throughout life to make new judgments when presented with novel sensory information. While the majority of these decisions may be mundane, some judgments, specifically those of a moral nature, require the whole of ones past memory. Our memories, simply put, are the basis of our identity as an individual.

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Addressing Excess Mortality from Cervical Cancer in Guatemala: Implementing VIA/Cryotherapy Screening
Grace Fletcher, Davidson College 11*

Guatemala has some of the worst health outcomes in the Western Hemisphere — a childhood stunting rate of 54.3%, a maternal mortality ratio of 290/100,000, and only 7 hospital beds per 10,000 people. Furthermore, lack of access to both preventative measures as well as acute care complicates the picture. Accessing and using the limited health resources available is even more difficult for Guatemala’s indigenous people, who comprise over 50% of the population and have been historically persecuted by and discriminated against by the Guatemalan state and military. One of three Guatemalan women is infected with the human papillomavirus (HPV) at any given time. For comparison purposes, the prevalence is only 13.3% of women in the United States. This highly transmissible, asymptomatic, and incurable sexually transmitted disease (STD) is the necessary cause of virtually all cases of cervical cancer or pre-cancerous cervical lesions.

Two factors explain the high prevalence of HPV in Guatemala. The first factor is the low prevalence of condom use in Guatemala, estimated at around 5%. Since HPV does not require the exchange of bodily fluids for transmission, but merely skin-to-skin contact, using condoms for sexual encounters can reduce but not completely prevent the transmission of HPV. The second factor is having a history of multiple sexual partners or having a partner who has multiple partners, which can significantly increase the risk of HPV. The latter is more characteristic of the situation in Guatemala, where over half of the population lives below the poverty line and many men leave their families and travel in search of work. Indeed, one out of 10 Guatemalans lives outside of the country. Extended separation from wives and girlfriends and a culture of machismo promotes male promiscuity, which has negative and often deadly consequences (like death from cervical cancer) for the women in relationship with these men. The women who contract HPV are deprived of their autonomy because they may have no idea about their personal risk, or may not be able to object to risky male sexual behavior. This becomes a moral issue because women are bearing the consequences of male behavior without making the conscious or informed choice to do so. It is especially unethical because women are paying with their lives for the sexual adventures of a partner they trust. A well designed and implemented cervical cancer screening program can mitigate some of this injustice.

Not only is mortality from cervical cancer unjust because it is based on the reproduction of hierarchies of power between the genders, but it is an excellent example of what has been called a “global health disparity.” Whereas cervical cancer is the most common cancer in women in Guatemala, killing about 50% of the women who are diagnosed, it does not make a top ten list of common cancers among American women. Indeed, 85% of the worldwide deaths from cervical cancer take place in developing countries like Guatemala. Over the past several decades, the incidence of cervical cancer has dropped by a staggering 70% in wealthier countries, while worldwide mortality from cervical cancer is expected to rise over the next decade, driven mostly by deaths in developing countries. Obviously, there are huge gaps between the quality and availability of screening and/or treatment in Guatemala and the United States.

This gap is based predominately on disparities in access to screening, which significantly lowers a woman’s chances of dying from cervical cancer in her lifetime. In the United States, most insurance companies will pay for a yearly Pap smear, and uninsured or low-income women have the option of inexpensive or free screenings through their local health departments. In Guatemala, the only cervical cancer screenings are available through private physicians operating in large cities, or through small, localized non-governmental organizations with a limited reach. For a largely impoverished and rural population, cervical screening is not an option. From a social justice perspective, disparities in access, both across and within a country’s borders are not acceptable and not ethical. Location should not be destiny— all women should have access to some sort of cervical cancer screening, regardless of their region or country of residence.

When women do not have access to cervical cancer screening, their right to health is threatened or infringed upon. The United Nations Universal Declaration of Human Rights declares that “everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services…” I contend that access to cervical cancer screening is so inextricably linked to adequate reproductive and general health for women that limited access to cervical cancer screenings is essentially the same as limited access to health, which is certainly unethical.

Furthermore, if pre-cancerous cervical lesions are detected before they develop into invasive, terminal, or high-grade cervical cancer, they are relatively treatable. Cryotherapy or surgery are two options available to remove the abnormal cells from the cervix. Cryotherapy in particular, as a non-invasive, outpatient procedure, is well suited to low-resource countries like Guatemala and very effective. Well organized screening programs have been shown to reduce both incidence of and mortality from cervical cancer by up to 90% in some cases. Another study showed that screening women just once in their 30s with VIA/Cryotherapy reduces lifetime risk of cervical cancer by

(Continued on page 13)
25%. Increasing to two lifetime screenings can reduce risk up to 65%. Thus, a diagnosis of pre-cancer or early-stage cervical cancer should not be a death sentence, especially because early detection followed by treatment is so effective in preventing deaths. Most deaths from cervical cancer in Guatemala are unnecessary deaths. Excess mortality, especially when deaths can be avoided through screening and treatment, is a moral issue that should not be accepted.

Thus, the challenge in developing countries like Guatemala is to implement a cervical cancer screening program that is closely linked to a treatment regime that will be effective, appropriate, and inexpensive. Support for VIA/Cryotherapy programs has been steadily growing over the past decade, as pilot programs across the developing world demonstrate their efficacy and feasibility. VIA stands for “visual inspection with acetic acid,” which as the name implies, is the process of flushing the cervix with table vinegar. The vinegar causes precancerous cells to turn white, allowing them to be seen with the naked eye. This approach to cervical cancer screening is also known as “see-and-treat,” because the cells identified as pre-cancerous are immediately frozen off of the cervix with cryotherapy. The proposed program in Guatemala is targeted toward the population of women aged 30-39, since most deaths from cervical cancer happen after age 40. Additionally, women in their 30s have likely been sexually active long enough to contract an HPV infection, which can take 10 to 20 years to manifest as cervical abnormalities. Doctors, midwives, and community health workers (CHWs) already operating in communities and health centers will be trained to provide the VIA/Cryotherapy screenings. Training for health professionals can be done in as few as three days. A complementary educational program will be instituted to educate women and their families about HPV, cervical cancer, and the importance of early detection, as well as explaining the VIA/Cryotherapy process and emphasizing the importance of condom use.

A VIA/Cryotherapy screening program is the easiest and most effective way to address the moral problem of excess mortality from cervical cancer in Guatemala. The other options are instituting an HPV vaccination program or implementing a similar screening program, except with Pap smears. The benefits of the VIA/Cryotherapy programs include: cost-effectiveness, both at start-up and per patient; that the procedure is non-invasive and can be done without anesthesia (unlike surgery); that it can be done “in the field” and does not require a hospital, clinic, or electricity; that there are few complications or side effects, only a short-term watery vaginal discharge; that detection and treatment can be done in one visit, eliminating loss of follow-up; and that unlike Pap smears, VIA/Cryotherapy does not require appropriate (and expensive) cytology laboratories, personnel, or transportation of specimens.

HPV vaccinations only protect against 70% of cancer-causing strains of the virus, and need to be delivered in a series of three shots, which requires a superior medical record and patient tracking system than Guatemala has currently. The vaccination series would also be prohibitively expensive. The vaccine is only recommended for adolescent and young adult women, because they are less likely to have already come in contact with the HPV virus, which limits the reach of the intervention. Furthermore, there is cultural resistance to vaccinating adult women in Guatemala, especially among indigenous people, because of belief that the Guatemalan government systematically sterilized women in the latter part of the 20th century. Thus, considering the benefits and drawbacks of VIA/Cryotherapy, HPV vaccination, and screening with Pap smears, it becomes clear that a program of VIA/Cryotherapy is the best choice for Guatemala’s excess cervical cancer mortality.

Mortality from cervical cancer is a moral problem because it reflects a gender disparity, a global health disparity of access, and is mostly unnecessary because of the effectiveness of early detection and treatment. Implementing a VIA/Cryotherapy program would significantly lower the incidence and mortality from cervical cancer in Guatemala, and is a better choice than Pap smears or HPV vaccination. Of course, this new program comes with ramifications, benefits and obligations for the individual woman being screened, her family and community, medical professionals, and the state. Many of those concepts are related to important ethical concerns, like informed consent, beneficence, and individual autonomy. These ethical concerns are important for the success and acceptability of the program.

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2WHO/ICO Information Centre on HPV and Cervical Cancer (HPV Information Centre), “Human Papillomavirus and...


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The government needs to be a part of this boundary establishing process. They need to define effectivity the intellectual property rights concerned with rDNA products, as “new life” as property is a novel ethical issue. Currently, researchers can secure patents for their genetically engineered life. In 1980, the Supreme Court ruled in Diamond v. Chakrabarty that a genetically engineered strain of bacteria that aids in the cleanup of oil spills could be patented. Soon after, the U.S. Patent and Trademark Office assented, declaring that non-human genetically engineered organisms were eligible for patent. With the constant new advances of science, we need to reexamine the legal implications of new knowledge and technology often.

Science stands at a new threshold, one at which we can touch the very basis of living existence. To researchers, there seems to be no limit on what can be accomplished with enough time and money. Nevertheless, we need to define self-imposed limits to what is done, so we can maximize the benefits of genetic engineering while minimizing the negative impacts on the sanctity of life and potential fallout for the naturally occurring world.

References & Further Exploration:


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Disclosure of Unsought Information

Kelly Wilson, Davidson College ’13

Situation: Through genetic testing before an organ transplant between a father and his daughter, it is discovered that the donor (the daughter) and recipient (her father) are not genetically related. As a matter of transplantation policy, donors and recipients each have his/her own physicians and transplant team (composed of a medical doctor, surgeon, social worker and nurses). The mismatch does not preclude the transplant. In this case, the doctors on the two teams disagree about whether the inadvertent discovery of “misattributed paternity” should be disclosed. Should the information be disclosed to both the daughter and/or father? Should doctors involve the wife/mother in this situation?

Although physician discretion is necessary in every circumstance concerning sensitive information, in this particular situation doctors should disclose the unsought information regarding paternity to the woman and her “father.” To respect patients’ autonomous rights in medical decision-making, physicians must provide patients with any information they possess that patients appear not to know which might play a role in their decision to consent to or refuse treatment. Knowledge of the fact that the daughter and the man are not biologically related could affect their decisions to donate and/or receive the organ. In order for them to provide an informed consent to the organ donation, their misunderstanding of the paternity status should be corrected by the physicians. This debate is particularly significant because “current practice in the United States and Europe seems to be that if nonpaternity is discovered inadvertently at testing, clinicians do not reveal it” 4. In many situations involving psychologically stable people, this is a violation of patient rights that undermines their trust in physicians and precludes the fostering of patient autonomy.

Duty to Disclose Relevant Information

The unsought information discovered by the transplant center may be pertinent to the daughter’s decision to donate and the father’s decision to receive the kidney, and thus it impacts their ability to make informed decisions 5. While the meaning of paternal information as it relates to transplants varies from person to person, some patients might only consider donating or receiving an organ from a biologically related family member. Interestingly, one study found that only “one third of U.S. transplant centers actively encourage spousal donation and at most about one quarter encourage the use of friends” (Spital). Even though there is little evidence that donations stemming from emotional relationships are inferior to those linked with biological associations, the fact that transplant centers do not encourage them the way they encourage biological transplants suggests an acknowledged difference in our culture’s openness to the two types of transplants.

If the daughter finds out that she is not biologically related to the man to whom she was planning on giving her organ, she could change her mind. Some might argue that this should be irrelevant in her decision because the socially defined role of father trumps any biological paternity. While this is a plausible point of view that some patients would agree with, it comprises a value judgment that physicians must resist because it is not universal. Doctors should not be making decisions for autonomous, competent patients; rather, their role is to provide them with the information they need to make the best decisions for themselves. Even if a physician does not agree with a patient’s motivations for donating (on a biological basis only, for example), he should not attempt to steer the patient based on his own values and ideologies. Not only does this information affect the daughter’s decision to donate her kidney now, but it also could affect her medical and reproductive considerations in the future. She has a right to know this information because when making decisions about having her own children, she may be deterred from doing so if she remains under the false impression that her offspring could have a high risk for inheriting the gene for the disease her father suffers from 2. Family medical history is also crucial as one gets older and becomes susceptible to a greater number of diseases. If the status of her paternity has been found to be different from what she currently believes, her

(Continued on page 16)
physician has a duty to inform her of this and change it in her medical chart so that she can be fully informed about her susceptibilities and correctly disclose this information to her future physicians. There are ways to manage anxiety, but letting someone make decisions (both now and in the future) based on false premises is careless and irresponsible, especially when they are medical in nature.

Finally, knowing one’s truth, his identity and where he comes from, is often important in order to fully understand oneself. Disclosure could result in family distress, but this reason is not compelling enough to shield someone from a basic aspect of his or her identity.

Objection to Disclosure

Opponents may state that disclosing information about misattributed paternity results in more harm than good. They base their argument on the grounds of the American Medical Association’s statement on disclosure in its Code of Medical Ethics: “Full disclosure is appropriate in all cases, except in rare situations in which such information would, in the opinion of the health care professional, cause serious harm to the patient.” Additionally, medical ethicist Daniel K. Sokol’s article in the British Medical Journal states that justifiable reasons for deception or withholding information from a patient include: “the prevention of great physical or psychological harm (including death), the exercise of kindness or compassion, the emotional or cognitive incapacity of the patient, and the reliable belief that the patient wishes to be deceived.” Those who argue that the physician should not disclose paternity information might try to justify their argument with one of these reasons. Yet, the circumstances surrounding this case do not necessarily fall into any of these categories. First, there is no apparent indication in this circumstance that the patients “wish to be deceived.” They have not expressed undue worry or apprehension that would imply they believe they would be better off not knowing this sort of information. Additionally, physical and psychological harm are unlikely because (according to the information provided) there was no indication that these patients were mentally unstable or possessed unusually delicate emotions to begin with. Thus, there is little reason to believe that disclosing this information would cause one or both of them to go as far as to inflict physical harm on themselves or others. Specifically in terms of psychological harm, some might say that this information could be so distressing that it outweighs any potential benefit of disclosure; however, researchers examining physician disclosure of medical errors concluded that just because information had the potential to cause distress did not justify non-disclosure.

In this particular situation it is likely that distress will result from the disclosure. The study also noted that many physicians mistakenly “equate upset with harm.” The potential distress and family angst resulting from disclosure can be mitigated through personal and family counseling and is not serious enough to outweigh the benefits of disclosing the information. The misattributed paternity might make the patients feel upset or experience dissonance, but whether it will be “harmful” and thus prevent them from navigating life or remaining rational is questionable. The key is for physicians to remain sensitive to patient emotions throughout the disclosure and either be readily available themselves or make arrangements for further counsel and therapy if needed. By disclosing the information to patients upfront in a controlled way, physicians may “actually prevent the psychological harm” that might result if patients were to find out later in another, less sympathetic way.

Protecting patients from bad news is now seen as an invasion of individual rights based on value judgments that may not be relevant to the patient’s goals. The very idea that the information will, with certainty, result in family turmoil or “ruin” the relationship between these two people is based on a value judgment that a biological relationship supersedes the emotional bonds two people can develop over time based on love and support. Some argue that paternity identification was “not the purpose of the test” and thus should be considered irrelevant. They say, “medicine has no role to play in exposing infidelity.” However, this stance approaches the issue in a limited way. The purpose of disclosure is not to call out a parent for her unfaithfulness; its purpose is to provide the patients with the information they need to make informed medical decisions both now and in the future. For example, routine tests reveal unexpected illnesses all the time, and even though people are not seeking out specific diseases, doctors still disclose inadvertent findings if they are medically significant. The same logic should apply in this case.

Critics further posit that paternity is a “non medical issue,” but this neglects the far-reaching scope of biological identity. Paternity is medically relevant: It potentially affects the daughter’s decision to have children in the future or to donate her organ to this man, whom she incorrectly assumes to be her biological father. Knowledge of paternity also affects her ability to fully disclose to future physicians her family medical history. Often, susceptibility to medical conditions is gauged by what runs in families. If the daughter is basing her judgment on incorrect information (that doctors discovered and had the ability to fix by correcting her incorrect assumptions) they have a duty to tell her. Information that contradicts her presumption that this man is her father could potentially not only affect the decision about whether to donate her kidney, but also her ability to make autonomous decisions about medical treatments in the future that rely on family medical history. Doctors might not have been expected to test for paternity, but because part of the HLA test included a paternity test that revealed the misattributed biological association, it should be disclosed. It is up to the patients to decide what to do with this information and determine whether it will factor into their decision to accept treatment, but if they don’t have it to begin with, they are prisoners to the doctor’s own judgments because their autonomy is undermined.
Health as a Human Right: Common Humanity and Rights to Equal Opportunity
Sara Maldonado, Davidson College 12

After the disturbing and clear violations of human rights seen during the World War II era, many world powers came together to form the Universal Declaration of Human Rights through the United Nations. Article 25 of this declaration states that:

(1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. (2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

While few would argue that the concept of health for all humans is something negative, some would argue that health is not a right, but rather a luxury. However, as we closely examine what most the Western democratic countries (such as the United States, England, and France) consider “rights,” we will see that health, or the opportunity to be healthy, is, in fact, a right by these definitions. As these countries are some of the wealthiest in the world, and therefore have the ability to provide those with the unfulfilled right to health, it is important to define health as a right by their standards. Defining health as a right by Western nations’ governments’ and citizens’ standards then morally obligates them to provide the opportunity of health to those without health.

The right to health can be defined as the following – the right to “equal opportunity of access to quality health care, regardless of gender, race, social economic and geographical facts,” as articulated by Wendy Austin 2. The word “health” includes things that create living conditions that are conducive to having good health, such as potable water, food security, proper sanitation facilities, and education. Many have noted that part of the confusion about a concept of health being a right comes from the use of the word “health” to embody all of these things. It is implausible for a government or organization to enforce the actual state of good health on all peoples of the world. It is, however, more understandable when we define it as the right to opportunities of access to all aspects that are necessary to create the aforementioned living conditions conducive to having good health.

As health care is necessary in order to maintain good health, it is also necessary in order to avoid premature death. Using the ideas of John Locke and many others, Western democracies founded much their governments on the tenants of man’s right to life, liberty, and the pursuit of happiness (as stated in the United States Declaration of Independence). In order to at least have life, humans must have access to health. Ergo, Western democracies inherently support the legal right to health. One may argue then argue that nations only have the legal obligation to provide health to its own citizens. However, while this may have been much easier to argue when nations were less dependent on each other, in today’s global society, many nations are all connected to the Western democracies in some form or another. Due to the lasting effects of imperialism and the newer movement of globalization, country borders become more and more arbitrary—we are all essentially connected and related 4,8. The challenge with the legal argument is simply that, while we view economic and political rights as necessary, we have yet to truly see the right to health in the same light—as worthy of protection from governments and international law bodies 4,6. As such, health is not perceived to be as important as other rights, and is devalued as a right. Therefore, as Paul Hunt articulates, “it may take some years before the right to health enjoys the same currency as other, more-established human rights” 6. This in itself weakens the clout of the legal argument for health to be viewed as a human right, although the argument itself is logical.

Many oppose the legal argument to view health as a human right. An opposing argument is that health for all comes at the expense of others, and therefore, health cannot be a right as it imposes a sense of duty on others. In a British Medical Journal article, Dr. Philip Barlow that universal access to health should be considered a “legal entitlement” as opposed to a human right because it imposes this “intolerable burden” on many others 3. However, although, providing all with an opportunity to health would impose a burden and a sense of duty on others, this does not mean that it is not a right. All Western democracies (and many other countries) consider life to be a human right, and we are all also legally entitled to life with our governments’ laws that protect our lives, by making homicide illegal, for example. In such cases, man’s right to complete autonomy

(Continued on page 18)
is overridden because some governmental guidelines are necessary in order protect humans’ right to life. The right to health could therefore easily override humans’ rights to economic liberty using the same reasoning.

While Western democratic ideals and globalization do provide a legal argument to view health as a right and help all humans to obtain that right, many have noted that the humanitarian argument is much more compelling. In fact, the humanitarian approach is “arguably the most common ethical basis for global health action,” calling on people to “respond to human suffering and realise human fulfilment by acting in a virtuous manner based on compassion, empathy, or altruism” ¹. As a humanitarian approach is perhaps the most common, it must be because people have found it most effective in raising support for global health action, which essentially is augmenting the number of humans who have a realized right to health.

The humanitarian ethical basis for health being a right depends on things such as compassion, empathy, and altruism. These three aspects are all fundamental aspects of the term “humanity.” It is widely accepted that all humans share this sense of humanity. Agreeing that we have a certain shared sense humanity that is partly inherent and integral to our “successful coexistence,” accompanied by the idea that health is a right, “simply illustrates that humanity is health and human rights writ large.” ² Therefore, affirming that humanity exists, we can deduce that the concept of health as a right is legitimate—because humanity is real, its components, including the right to health, are as well.

Another argument opposing the classification of health as a right of any kind is a correlation-based study that defines health care as a luxury. Past multiple-country studies have concluded that per capita income is, in fact the “most important determinant of per capital health expenditure...leading to the conclusion that health care is a luxury rather than a necessity” (Sen 147). However, Anindya Sen concluded otherwise, showing that this deduction is false. In his study, he showed that as health care costs increased, health care expenditures do not decrease (160). Therefore, as cost does not deter consumption, Sen concluded that health care is a necessary good rather than a luxury, contradicting what many had concluded before (160). Because health care is not classified as a luxury but rather a necessity, we can conclude that it integral to maintain overall good health. As good health is necessary for humans to maintain their right to life, we can conclude that health is a right.

Although commonly misunderstood, health is a right. Obviously, we have no right to be born healthy and have a perpetual state of perfect health, as aging is a natural process that involves deteriorating health. When people properly understand what a right to health means, this “standard of health has a profound contribution to make toward building health societies and equitable health systems” ³. The right to health means that humans all have a shared right to have “equal opportunity of access to quality health care, regardless of gender, race social economic and geographical facts,” as well as to living conditions that are conducive to having good health ⁴. Because Western democratic countries founded their governments on ideas such as humans’ rights to life, liberty and the pursuit of happiness, we can deduce that these ideas encompass humans’ right to health as well because one cannot have life in the complete absence of health. Due to the effects of globalization and the lasting effects of imperialism, the Western democracies and international legal bodies with the political clout and monetary means are arguably obligated to provide legal protection to countries that are dependent on them. However, the humanitarian ethical basis for considering health to be a right is generally much more effective as it appeals to the humanity that we all possess and are morally guided by. Because most agree that humans have the innate right to life, they would then have to agree that we all have the innate right to health. To deny that humans have a right to health would be to deny that humans have a right to life. As very few people would be willing to admit that, we are able to conclude that humans do have a right to health.

References:


The right to health is therefore better thought of as “what we as a society do collectively to ensure the conditions in which people can be healthy.” A theory of “progressive realization” would help ensure that the full right to health is granted through a series of goals that do not have to be uniform reflecting the various resources and cultures of different countries.

A theoretical human right for health allows a basic standard for human dignity to be met. Currently, no authority is set up to enforce the right to health. The primary response to questions regarding the right to health is still mainly humanitarian. Thus, health inequities began to grow, as no obligation to human rights exists to ensure the constant effort to maintain the base line of right to health. The right to health is a positive one that the government must work to promote, merely practicing a negative right to health will not allow the redistribution that is necessary for everyone to have access to healthcare and health determinants. However, human dignity demands that everyone have their basic need to health met so that they can have the ability to have the base upon which they can make health decisions and participate meaningfully in an economic manner in society.

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References
9 Foley, K. Lecture.

Frederick Womble Speas Bioethics Symposium

“Contemporary Challenges in Medicine and Research”

April 14, 2010
C. Shaw Smith 900 Room

5:00 p.m. Welcome and Introduction Lance Stell, Ph.D., FACFE
Kristie Foley, Ph.D.

5:00 p.m. “Challenges of Globalization and Transnational Bioethics” Catherine Myser, Ph.D.
Founder, Bioethics By and For the People

6:20 pm “Clarifying Conflict of Interest” Howard Brody, M.D., Ph.D.
University of Texas Medical Branch

7:05 pm “Money in Health Care: Sin or Salvation” Thomas P. Stossel, M.D.
Brigham & Women’s Hospital, Harvard Medical School
Future Considerations

In this particular case, there should be full disclosure of the misattributed paternity to the daughter and the father, the two patients considering treatment. Both patients have a right to know this information, which contradicts their current understanding and has the potential to affect their decisions to donate/receive the organ. Some would argue that the mother has the right to know first, but she is not involved in this medical decision – she is not a patient of these physicians. Therefore, the daughter and father can decide whether they wish to tell her about the finding or not. The purpose of the test (and the subsequent disclosure of its findings) is not to identify infidelity; rather, it serves to provide information so that the patients considering treatment could make fully informed decisions. The mother is irrelevant.

Perhaps one way to ameliorate this situation’s moral dilemma would have been to explain to the patient(s) ahead of time that paternity is tested for as part of the HLA test. One could ask them if this information is pertinent to their decision to donate and whether they want to be informed about paternity, regardless of what it is. Another approach would be to explain to the patients after the testing: “Unsought information has been discovered that could potentially impact your decision to donate, do you wish to be told what this consists of?” Despite the method of disclosure, the transplant center should be able to provide subsequent counseling if necessary.

Regardless of action taken, this is a sensitive issue that requires careful consideration of patient interests and attention to emotion.

References:
6. Kelly Wilson 13’ is a prospective Neuroeconomics major at Davidson College. She plans to attend business school following graduation.

References:

Once they agree to participate in a research or clinical trial? If patients’ tissue and DNA prove to be valuable to research, should they have a right to reap financial rewards?

These are very complex issues that legal rulings and standards cannot answer alone. As bioethicist Karen Maschke of the Hastings Center reminds us about the case of Henrietta Lacks, “what is legal may not be the same as what is ethical...People want to know. Science has to be open and honest.” It is critical that Lacks’ family never knew what scientists were doing with Henrietta’s cells. Although greater disclosure to patients may lead to excessive bureaucratic requirements on researchers that slow advances and discourage clinical research participation, patients have a right to make competent, autonomous decisions about the use of their bodies. A failure to uphold truly informed consent to research could result in a violation of bodily integrity and perhaps even economic or social exploitation.

The cases of Henrietta Lacks and Myriad’s patents on cancer genes help illuminate the conflict in medical research between the enduring search for knowledge and the rights of individuals who make this research possible. With the prolifera-
The Actuality of Autonomy: A Personal Reflection on Patients’ Rights

Maddie Chalfant, Davidson College 11’

In any introductory course at all related to medicine, one learns the four essential tenets to medical ethics: patient autonomy, beneficence, non-maleficence, and justice. They are the four basic principles that guide actions in medicine. While these principles may seem apparently simple and concrete, I did not realize the actual application, and perhaps more importantly, the true significance of these four words is anything but. I had no idea of the actual meaning of autonomy until I became a patient.

The summer before my sophomore year at Davidson, I became acutely ill with a gastrointestinal virus. This virus induced such violent retching that I tore my esophagus. Vomiting blood in and of itself is scary, but the virus wasn’t done with me yet. It settled in my gall bladder, resulting in cholecystitis. While there are many different presentations of cholecystitis, the vast majority of cases involve gall stones, severe upper right quadrant pain, abdominal fullness, fever, or clay colored stools. I experienced none of these. Instead, I had constant nausea and vomiting for three weeks, during which I became progressively worse. During the road trip from Colorado back to Davidson, I was so sick that I couldn’t keep most liquids down and frequently had to ask my Dad to pull over on the side of the highway so I could vomit. My dad fondly refers to this trip as the time I vomited across the country (he also claims to have post-traumatic stress from the trip).

When we finally made it back to Davidson, I was still vomiting – even after sucking on a small ice chip. After I passed out in our hotel room, I went to the hospital where I was admitted. After 5 days, I was still vomiting even though I hadn’t ingested anything and was on anti-nausea medicine in my IV. Despite two CT scans, an ultrasound of my abdomen, a gastric emptying study and a gall bladder function test, the doctors could not diagnose me. Some thought that my gall bladder was inflamed; one doctor thought I had a somatization disorder. With no other options—because, when you get down to it, a person really can’t live on an IV full of sugar water for the rest of their life— they called a surgical consult who suggested that I have my gall bladder removed. The next day, I was given a consent form to sign as an orderly waited to wheel me down to the OR.

When the nurse handed me the consent form, my first thought was, “Why are you giving this to me? My mom is right there,” but then I remembered I was 18. If this had happened just one year earlier, my mom would’ve signed the form. I wouldn’t have been responsible for the outcome, good or bad. My second thought was “What if you’re not really sick? What if that doctor (who was an conceited jerk) was right, that this is just a somatization disorder?” Finally, I had the realization that led to the separation of my gall bladder and I: “What other option do I have!” So I took a deep breath, illegibly scrawled my name on the form (as it is very difficult to write with an IV in the vein in your hand), and headed to the OR.

Luckily, everything turned out alright. My gall bladder was infected and inflamed. And I was able to eat my first meal in nearly a month without getting nauseated. Honestly, it was probably the best meal of my life (which is saying a lot, considering it was dry chicken and rice).

I am sharing this information not to garner sympathy, but rather to highlight two obvious yet frequently overlooked aspects of medicine. First, while seemingly obvious, is that being a patient is scary. Patients are in distress, be it pain or fear or both. More over, the fiduciary relationship between doctor and patient renders patients utterly dependent upon the opinion of their doctors. Secondly, the combination of these two facts diminishes the patient’s capacity for autonomy. Their distress and dependence can, and often does, manifest itself in a desire to not want autonomy. By directing their own care, patients become partially responsible for negative outcomes and complications. For some people, the fact that they could be responsible for their own decline in health may be more frightening than the prospect of getting worse. It is easier if someone else simply makes the decision, for if there are complications, the patient can blame and even hate the person who made the decision. More importantly, patients will do and agree to procedures that they normally would not just to end their own suffering.

Thus, doctors and ethicists alike need to recognize that patients do not actually have autonomy. The basic principles guiding medicine are not as simple as we would like to believe. It is too easy to make black and white judgments based on these abstract concepts in medical ethics; one must only forget that real human beings are involved. However, it is only through the recognition that patients are people in distress who do not have full autonomy, and that these four basic tenets are only guiding principles whose definitions can change based upon the context of the situation that we can reach a conclusion. The application of these concepts will never be as simple and clear-cut, for life is often messier than we would like to admit.

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A PUBLICATION OF THE MEDICAL HUMANITIES
PROGRAM OF DAVIDSON COLLEGE

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