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Preface

What are some of the most intriguing and contentious issues in Bioethics? Ask the prescient writers who have submitted their articles for this edition of the Columbia University Journal of Bioethics. And it is not just because the authors have been discerning enough to identify the issues. No, the authors offer us their perceptive opinions regarding not only what we need to be concerned about but what we can do to resolve these issues. Importantly, they also foretell the promises that our biotechnology will offer to promote the welfare of our nation and indeed the world.

This edition of the Journal is replete with issues that make us stop and take notice on a variety of new technologies such as using "smart drugs" to gain a mental edge over other students, or to transplant stem cells into an aged ovary that would fully restore child-bearing potential. The role of cultural in bioethics presents profound dilemmas – hymenoplasty is one of the fastest growing trends in the US, with a hymen implant complete with the insertion of a gelatin capsule filled with a blood-like substance that will burst during intercourse, simulating bleeding, for those who need to or want to suggest virginity. Consider the new pressure placed on surgeons, knowing that this procedure is designed to mislead family members. The brain, our ultimate scientific frontier, raises profound considerations which challenge us when viewing the beautiful images of our brains in action. But have we finally obtained the ability to detect lies directly from the brain that may provide the key that unlocks our most private sanctuary -- our mind?

Our authors discuss fully the interface between science and ethics where lies the notoriously gray area, where the intended and unintended consequences surface. For responsible science to go forward, these consequences must be revealed and confronted. Many of these outcomes are dazzling and sensational. But ultimately, they all will have an impact on our lives and even on our planet. Reading these exceptionally well thought out articles that are balanced to present the pros and cons, the benefits and the harms, the gains and the setbacks, certainly gives me great confidence that this cadre of students is fully aware and ready to take on the challenges that our creativity present. It is a great privilege to promote these discerning critics who will resolve the challenges that will surely confront us as we face the ever-new frontiers in science. They will ensure that we implement the bioethical imperative: it is not what can be done; rather it is what should be done.

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In 2009, the election of Barak Obama as President of the United States and the sharp decline in the American economy had a tremendous repercussion on biomedical research. President Obama re-evaluated how federal funding should be applied to stem cell research and initiated an economic stimulus package to promote biomedical research. While research funding resources have dramatically declined new discoveries in biomedicine continued to develop and advance. Many of the articles in this Journal address some of the most exciting advances in biomedical research and focus on the bioethical issues that emerge from these new discoveries. The authors of papers published in this Journal have voiced their opinions and proposed innovative insights and solutions in response to challenging bioethical issues. The common philosophical foundation of all of these authors is the mantra that "good bioethics begins with good facts". Once the scientific background is described, the authors then discuss and attempt to resolve the emerging bioethical issues. These student contributors are aspiring scientists, physicians, lawyers, and philosophers whose thoughts and opinions are the heartbeat of this Journal. These students will emerge as the front line of scientific and medical discovery. Their future innovative research and ability to communicate science to the public will elicit and inspire bioethical debates. Furthermore, they will become essential players in helping society resolve many bioethical dilemmas. In addition, this year we have included guest faculty from Columbia University to write for our Journal.

This year's Journal volume continues its tradition to include a special supplement from university students who participated in an innovative cross-cultural educational program called Bioethical Cross-cultural Educational Program (BIOCEP). In 2009, almost 40 student from eight different countries attended a special two week program at Mahidol University in Bangkok, Thailand exchanging ideas and learning how culture and religion influence bioethical dilemmas. Their articles reflect some of the lessons derived from this program and highlight the importance of cross-cultural humanistic values in confronting global bioethical conflicts.

John D. Loike, Ph.D.

Course Director – Frontiers in Bioethics, Co-Director of Graduate Studies, Department of Physiology

Molecular and Genetic Interventions

Do we really know what we're eating?

Author and Missing References!!

On your next trip to the grocery store, take a look at the labels on the products you buy. Do you really know what you're eating?

You might be thinking, "Of course I do." The first area you encounter when you enter almost any supermarket is the produce section. Have you ever seen the familiar "Nutrition Facts" and "Ingredients" labels on fresh fruits and vegetables? Usually, information about the origins of our fresh produce is limited to words like "Farm Fresh," or "Organic" written on the signs above the piles of brightly colored fruits and vivid green vegetables. An apple might have a small sticker that identifies its country of origin, and most of us peel it right off without a second thought.

The little stickers are used by the cashiers to charge you the right amount at the checkout counter, since they contain a short, four-digit Price Look-Up code, or PLU. Some produce is labeled with a fifth digit prefixing the four-digit code; a "9" indicates that the item is Organic, and an "8" indicates that the item is Genetically Modified. PLU codes are defined by the International Federation for Produce Standards (IFPS), and are currently one of very few, if not the only, forms of labeling that positively identify food that is a product of genetic engineering in the US.

But what about those of us who skip the produce section? 86% of all corn produced in the United States is genetically modified. Some strains have been engineered to be more resistant to various herbicides, others have been given genes from the bacterium Bacillus thuringiensis (Bt) to make

kernel color or content of specific molecules. Moreover, virtually all processed food available on our local shelves is loaded with High Fructose Corn Syrup (HFCS), including soft drinks, boxed pastries, and even Oreo cookies. This means that practically all of them contain ingredients that have been derived from genetically modified organisms, which means that we are consuming all of the proteins that confer the herbicide and insect resistance along with the intended food. Furthermore, , most animal feed is teeming with genetically modified plants as well, so those of us who eat meat are getting an even more concentrated dose of anything that might get absorbed by the animal.



The first genetically modified plant, an antibiotic resistant tobacco, was introduced in 1983. A decade later, Calgene's "Flavr Savr", a delayed ripening tomato became the first commercially

available GM food. Thus began a biotechnology revolution that has resulted in genetically modified ingredients in some 70-75% of processed grocery products, as estimated by the Grocery Manufacturers of America. These "First Generation" GM crops, as they have come to be called, contain modifications mainly aimed at improving farmers' bottom line: larger yields, robust pest resistance, and increased herbicide tolerance. Future developments include plans to engineer hypoallergenic foods and "pharmacrops" that will naturally produce disease vaccines. GM foods have provided real benefits, with more on the horizon. Why, then, are we so concerned about the labeling of these products?

One concern is the threat of unintended side effects. GM crops are modified by transferring the genetic material from one species into the genome of the crop to be altered. When this gene is expressed as a protein, the GM crop is hopefully endowed with some useful trait. However, the human immune system can detect the foreign nature of these proteins, and this can be dangerous for people who are allergic to the donor species. For instance, in 1996, Pioneer Hi-Bred spliced Brazil nut genes into soybeans to increase the methionine content of their soy. Blood tests on Brazil nut sensitive individuals confirmed that their antibodies attacked the Brazil nut protein in the soybean, indicating that a systemic response was produced that could lead to anaphylactic shock in people with severe allergic reactions. As much as 25% of Americans display some form of food-sensitivity, so allergen transfer is a very real

Another major concern is the long-term effects of GM crops on the environment. GM seeds are clones of each other, meaning they are completely identical in their traits and survivability. This "sameness" can lead to a loss of adaptive survival means, so that entire populations can be wiped out by one plant virus. This can have disastrous effects when you consider that the vast majority of soy crops in the United States are derived from

the Monsanto company's GM seed. Other crops have been modified to exude the Bt endotoxin pesticide from every one of their cells, leading to a large buildup in the soil that would not occur under natural conditions. This buildup can have far reaching effects on the insect ecology of the soil, removing the plant's primary insect predators while allowing secondary predators to flourish. The pesticide resistance may also be given to the native weed population via horizontal gene transfer, creating a strain of super-weeds that are difficult to kill. Consumers with environmental concerns need to be made aware of these dangers.

Many of the tests proving the safety of genetically modified foods are performed by the companies that own and produce them, and, understandably, have been designed so that their products pass as safe, regardless of whether they are actually safe for human consumption or not. The European Union, Australia, and Japan all require the labeling of GM food that is sold within their borders, and it is the responsibility of any government to ensure that its citizens are



protected from the interests of the corporations. Given the rapid and practically unnoticed proliferation of GM foods in the average American diet, it is time for labeling of GM foods to be required in the US as well, so that consumers can be better informed about what they are voluntarily taking in to their bodies.

Creation of a Bacterial Cell Controlled by a Chemically Synthesized Genome

Meixin Wang & David Shiovitz

Earlier this year, researchers at the J. Craig Venter Institute successfully synthesized and assembled the 1.08 megabase pair Mycoplasma mycoides JCVI-syn1.0 genome [GenBank accession CP001621] (Gibson, et al., 2010). They started with a digitized version of the genome sequence and were able to transplant the synthesized genome into a M. capricolum recipient cell lacking all genomic information. The new cells, called M. mycoides, were fully programmed by the synthetically designed genome, possessed the phenotypic properties dictated by the designed DNA, and were capable of continuous self-replication. This technology introduces the capacity to fully customize genomic information with designed deletions, additions, polymorphisms and mutations on a computer, giving the designer the full potential to "create" a user-specified organism (Editorial Staff, Nature, 2010).

The use and modification of a fully synthetic genome in a viable organism marks a significant technological advancement over other genetic engineering

techniques that target individual genes and minute sequences. This discovery opens the door to a variety of potential applications, from creating increasingly accurate and customizable disease models to discovering new genetic sequencing that can cause disease resistance. In essence, Venter and his associates have demonstrated that our biological structure can be

manipulated to "create" what we identify as life. Venter's methods even allows advanced genetic engineering of organisms that have as of yet proven unable to be genetically modified.

Despite the synthetic nature of the engineered organisms, they have tremendous potential to model and provide insight into natural phenomenon. For example, removing sections of any portion of the genome can help identify elements that are essential for natural functioning of the organism, enabling the development of more targeted pharmaceuticals. Scientists could better link genetic history to natural history, for example by examining extinct mycoplasma species in a resurrected mycobacterium. New organisms with desirable properties can also be generated with a much-accelerated speed. For example, researchers at the Venter Institute are looking for ways to construct genomes that would allow photosynthetic bacteria to use light energy to produce hydrogen gas from water.

Overall, such a powerful technology sparks the imagination for projects that are truly only achievable on the wholegenome level.

Some may claim that Venter and his colleagues are not actually creating life, but rather simply reproducing it from known DNA. This technology certainly allows for a level of customization of organisms previously undocumented, but when it comes down to whether the organism is actually new, the answer

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WAY THEY'RE NATURAL! manipulate it. Thus, in response to claims that this technology may result in God-like creation, which is a dominant social and theological issue in bioethics, the mere transplantation of synthetic DNA into a mycobacterium itself doesn't quite send shivers down your spine.

This is not to say that this technology and its descendants do not have any potential to spiral wildly out of scientists' control. Even the simplest of organisms can take on unpredictable properties as it reproduces, adapts, and mutates, such as the immortal HeLa cell line used for cancer research that grew rapidly due its remarkable robustness and proliferation and has ended up contaminating other cell cultures in laboratories. Since these technological advances are clearly made in a barely explored field, it is impossible to formulate well-defined and watertight protocols. Methods of preventative thinking and risk analysis must be innovative and well thought-out.

The consequences of going from a humble synthetic cell to a synthetic organ to a synthetic animal, and perhaps even the jump to creating an entirely novel genome, is something that scientists must consider. The differences may seem small at first, but create a snowball effect. For instance, imagine that a synthetic heart saved the life of a patient. The patient himself would not be considered bionic or a synthetic organism, simply a fortunate individual with a synthetic heart. Yet at what point does the synthetic field give us the "ick" factor? How many synthetic organs can one person have before they are considered not fully human? This recalls the movie Repo Men, set in a future in which artificial organs can be bought for credit but are often violently reclaimed by the company's hired guns. Humans with artificial organs on which payments were overdue are viewed as extra cash who are coldheartedly sliced open on the spot to retrieve the organs. Human dignity in this movie had been reduced until organ repossession had

become the status quo and society was content with the state of matters.

Moreover, in the future, it may be possible even to create entirely new life-forms, not simply to synthesize them. Imagine a whole new species, living and reproducing and continuously changing, borne from one misshapen experiment. This would clearly be categorized under playing God, disturbing the natural order of things, and other metaphysical taboos. Not only human dignity, but also supernatural dignity comes into consideration.

For instance, does this synthetic cell prove that there is no vital force, which many philosophers claim differentiates the living from the nonliving—or have scientists successfully fabricated this vital force? Its theological significance must then be contemplated, as there are deeply entrenched views in Christianity, Islam, and many other religions that maintain the existence of such a life force endowed by a creator. Even if science cannot currently offer a definitive answer to support or disprove these convictions, the creation of synthetic DNA by itself stirs these deep-set beliefs and opposition to attempts at synthetic life. In a nonreligious context, it challenges the dogma that all life arises from existing life, and lends more matter the study of abiogenesis. More importantly, how would science and religion change their views, if at all, on the significance of natural life? There is much to discuss concerning humans' role in a future with synthetic organisms.

Yet the opposite of these fears could also be true. The species with such a programmed synthetic genome may be able to be easily contained within their experimental environment, and be nonthreatening if ever exposed a natural ecosystem. Synthetic organs and organisms may be another idea that the church and the public will become accustomed to, as they have to in vitro fertilization, genetically enhanced plants, and organ transplants.

However, it is certain that security measures must be taken to ensure the safety and ethical status of this technology. The question then presents itself as to how we deal with not just this technology, but the technologies that will inevitably result from this advancement. Should genetic engineers of the future not just select healthy embryos for IVF, but design the embryos with certain characteristics and traits that the parents or society deems desirable? Could two species be combined using this technology and cloned as an entirely new species? Because this technology is unprecedented, a new approach is needed to resolve the bioethical issues that accompany it. The methods and materials with which to synthesize an entire genome are beyond the capacity of most labs, but could be routine within as little as five years. There is a lack of international regulations for synthetic biology, although within the United States. Obama recently asked his council to consider the wider significance of synthetic biology, but such efforts have not resulted in definitive government policy. The essential issue is not the synthetic cell itself, but the "anticipated power of synthetic biology" in the context of the medical, commercial, environmental, and ethical issues it raises.

One such security measure could address the primary concern that genetic modification may inadvertently cause dangerous genetic combinations. Software used to manipulate genetic sequences for synthesis should be monitored to detect deviations from normal standards of genetic manipulation. In addition, facilities used to initiate new genome lines should be standardized and secured both to test observe the natural development of these new genetic lines as well as to prevent any tested lines from being released into the general population.

One possible solution to mitigate issues surrounding the creation of new species and their natural evolution is to prohibit the use of this technology in higher life forms. Researchers would still be able to learn from the technology without compromising the natural life order or natural evolution. In its current manifestation, this technology walks a fine bioethical line. The more pressing concern is the imminent adaptation of this technology as new applications are tried and proven. The uncertainty of what will be attempted in the future highlights the importance of developing a commission or urge clear government policy to oversee and regulate the use of this technology as it develops into the next decade.

References

Editorial Staff, (2010), Challenges of our own making. Nature 465 (2010), 397. Online 26 May 2010.

Gibson, D. G. et al. (2010) Creation of a bacterial cell controlled by a chemically synthesized genome. Science 329, 52–56.



Live Long or Die Trying- transfer to BioCEP section Atara Nightingale

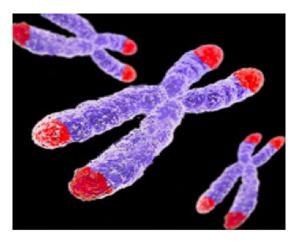
If you were given the opportunity to live forever, would you? Perhaps the notion of living forever sounds a bit like science fiction, but many of us would admit that we would like to live longer, especially if we were sick. This generation likes to break the rules of age-appropriate behavior and disdains the idea of retiring, resting, slowing down, giving up, and ceasing to strive (Walsh, 2010). Whether it is ten daysor a year, prolonging life is our survival instinct. While the last few decades have shown remarkable advancements in anti-aging techniques on the skin's surface, recent groundbreaking research has yielded a method to fight aging on a more cellular level.

Telomerase is one enzyme that has profound effects on the aging process and is currently under close scrutiny. The telomerase enzyme protects our DNA by renewing the telomeres (repetitive regions of DNA) attached to our chromosomes (Dreifus, 2011). As we age and our cells undergo many cell divisions, telomeres become depleted and DNA replication can no longer take place. At around the age of 45, our body stops producing telomerase, which means that our telomeres can no longer be renewed. It is no wonder that around this age, the true signs of aging kick in. Our telomeres at this stage have become shortened and are no longer capable of regenerating tissue (Foddy, 2011).

New studies have shown that shortened telomeres can cause illnesses associated with aging such as diabetes, heart disease, and Alzheimer's Disease (Hooper, 2011). The notion of reversing or slowing down the aging process became a possibility when biotech firm Geron identified the telomerase gene. Now that the gene has been mapped out, researchers can devise a telomerase-stimulating drug that can help increase the amount of telomerase in our bodies and reverse the aging process. This has

been a tricky feat since telomerase may be capable of stimulating cancer-inducing cells in our DNA. Another hypothesis is that a decrease in telomerase could increase cancerous cells.

Until late 2011, scientists were unsure which hypothesis is correct. Biologist Ronald DePinho and his team at Harvard University discovered that they were able to deactivate the telomerase gene in transgenic mice, which enabled the mice to age at an accelerated pace (Hooper, 2011). When DePinho chemically re-activated the gene, the effects of aging were reversed within a month. As he describes in Nature magazine, the mice returned to a stage of being physiologically equivalent to young adults. This was a major breakthrough because these mice were



functioning normally and didn't display signs of having any increased cancerous cells. DePinho's discovery leads us to question if we are capable of doing the same thing to human cells, that is, to create a drug or gene therapy capable of controlling our telomerase production. We are living in an age where humans frequently go under the knife to look more youthful and remove any signs of wear-and-tear on their skin. If we can intervene and manipulate the inevitable

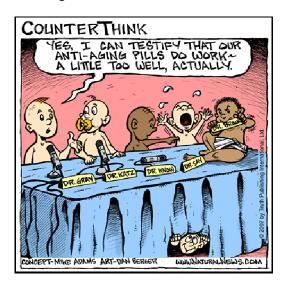
telomere-shortening is only one factor contributing to age-related degeneration. Other factors such as genetic disease, cancer, glycation, and oxidation need to be addressed since they contribute to cellular wear and tear.

While new discoveries constantly being made in the field of human longevity and anti-aging, we are also posed with a plethora of ethical challenges. Critics of anti-aging interventions say we need to examine the possible personal, social and economic outcomes of prolonged lifespan (Turner, 2011). Once we are able to treat the diseases associated with aging, we will need to reassess the way we decide who deserves disability payments and how to deal with retirement. If we are capable of manipulating the process of aging, what will determine the differences between health, disease, and disability (Foddy, 2011)?

Another concern is in the way many companies market anti-aging products, which may cause the consumer believe that they are indeed capable of living prolonged or immortal lives. Many organizations found on the internet will market their products as scientific breakthroughs despite the fact that they have not published any peer reviewed studies proving their treatment to be scientifically correct. The consumer can be easily bought into believing that they are buying a legitimate anti-aging product. Biogerontologists, geneticists, bioethicists and policy-makers need to protect citizens from potentially harmful, non-therapeutic and often costly products (Turner, 2011).

One critic of biotechnology's quest on human longevity is Leon Kass, Chairman of the President's Council on Bioethics who argued that "Victory over mortality is the unstated but implicit goal of modern medical science, indeed of the entire modern scientific project, to which mankind was summoned almost four hundred years ago by Francis Bacon and Rene Descartes" (Turner, 2011). Yet, as one can argue,

what is so wrong with prolonging life or reversing the process of aging if medical ethics instructs us to save a life when we are capable of doing so? Today, Doctors dedicated to saving lives encounter inevitable health problems that come along with old age. Would lengthening one's life be a form of saving them from illness or disease? Furthermore, if life-extending therapies become rampant, than how will we decide what the "appropriate" age of being elderly is; to what extent are doctors obligated to care for them? At this stage, the line between disease, age, and disability may become blurred whereby family members and doctors will be forced to decide whether or not a life is worth extending.



As our biological clocks tick onward, the overall human life expectancy is constantly increasing and we are faced to question whether the benefits of this outweigh the consequences. As researchers make headway in disease prevention and health standards are being improved, each generation is outliving the previous one.

Recent progress with the telomerase gene is just one aspect to lengthening one's life. Some

Foddy, Bennett. "Our Future as Human Lobsters." Web. 28 Aug. 2011. http://blog.practicalethics.ox.ac.uk/2010/11our-future-as-human-lobsters/#more-26

Hooper, Joseph. "Hey-Wanna Live Forever?" Elle Magazine. Aug 2011: 152-153. Print.

Shay, Jerry W. "Aging and Cancer: Are Telomeres and Telomerase the Connection?" Web. 28 Aug. 2011. http://www4.utsouthwestern.edu/cellbio/shay-wright/research/faq/sw faq.htm>

Turner, Leigh. "Biotechnology, Bioethics and Anti-Aging Interventions." TRENDS in Biotechnology. 22.5 (2004) Web. 28 Aug. 2011.

Walsh, J. "Never Say Die: Who Wants to Live Forever?" The Independent. 10 July 2010. Web. 28 Aug. 2011. http://www.independent.co.uk/news/science/never-say-die-who-wants-to-live-forever-2018292.html

Mind and Body

Swallowing Your Fear: New Breakthroughs in Anxiety Management

Pamela Lu and Carla Williams

Anxiety and fear: These two interrelated emotional responses to stress stimuli are usually experienced briefly and intensely and allow for fast recognition and response to danger, making extremely them an useful tool forsurvival. Without these emotional responses, the human race, for instance, may have become extinct long ago. However, in certain cases of extreme stress, maladaptive neuronal remodeling can occur, resulting in an animal or individual being trapped in a constant state of high anxiety. Although it has been well documented that only a minority of individuals who have been exposed to extreme stress (i.e. psychological trauma) actually wind up developing anxiety disorders, the reason as to



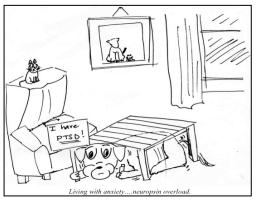
why such development only happens to a subpopulation is unknown. In a 2011 Nature Letter, Attwood et. al. investigate the cellular mechanisms behind anxiety behaviors.

By examining mutant mouse models that are neuropsin- deficient, researchers were able to determine the pathway along which neuropsin

controls anxiety behaviors. In wild-type mice, stress-induced neuropsin-dependent cleavage of an EphB2 protein occurred, resulting in the dissociation of EphB2 from an NDMA receptor subunit and a greater turnover of EphB2 receptors. Ultimately, this greater turnover enhanced the NMDA receptor current and upregulated Fkbp5 gene expression, which subsequently led to greater displays of anxious behaviors. In mutant mice that lacked neuropsin, the same stressful situations induced no such increase of anxious behaviors, thus pointing to neuropsin induced cleavage of EphB2 as the culprit behind anxious tendencies (Atwood). There are a number of ways in which this information about the signaling pathway behind anxiety has been better elucidated can be used. Heightened fear and anxiety are not only symptoms of post-traumatic stress disorder (PTSD), but indicate a plethora of other related disorders. Persons suffering with phobias, social anxiety disorder, panic disorder, agoraphobia, generalized anxiety disorder, obsessivecompulsive disorder and acute stress disorders may all benefit from treatment with neuropsininhibiting compounds. However, by altering the expression of the genes within the amygdala, the brain area that plays a role in controlling and storing responses to emotional events, there is certainly a risk of permanently altering how an individual's emotional responses processed. This brings into question what exactly makes up a person's individuality and identity, since emotional connections have often been cited as a characteristic that makes human beings a unique species. By altering the gene expressionin the region of the brain that controls emotion and emotional memory storage, would one be changing his or her personality? Or,

from a more generalized viewpoint, does science run the risk of diminishing some of the 'humanness' of the individual by altering the amygdala's emotional memory- saving mechanism? These are all issues involving the preservation of human dignity that arise from the use of new drugs that directly and permanently affect brain activity.

Contrary to current pharmaceutical products like Xanax and Prozac that are widely used to temporarily relieve anxiety, drugs developed to affect this anxiety pathway may open the door to more permanent treatments. A permanent, or at least long term treatment, can be a much more attractive alternative to something like Xanax, which circulates throughout the body for at most only 8 hours per dosage. With our current culture of over-medication, the possibility of a long-term solution for an issue as prevalent as anxiety is something that would be quickly snapped up by our neurotic society. The overzealous drug



market could prompt a rash adoption of the new treatment before long-term studies have been done. For an organ that is as poorly understood as the human brain, quickly manufacturing and distributing such a new, powerful drug could lead to serious, irreversible consequences. These consequences can even evolve into even greater ethical issues for society to deal with.

The present medication used for anxiety

disorders such as Post Traumatic Stress Disorder (PTSD) is believed to induce an alteration in the patients' response to their environment. However, without natural stress responses to govern their actions, people would live without restraint or without the debilitating fear of consequences. Thus, wide use of this inhibitor has the potential to lead to chaos. Moreover, if such technology was to be utilized in warfare to generate "perfect soldiers" that are desensitized to stress, war could become a very bloody affair. While the soldiers will no longer be encumbered by their fear and/or anxiety, they would no longer be able to access the effects that these emotions produce like caution. In wartime, the reflex fear response is one of the most crucial instincts a soldier can rely on. Many soldiers have cited their 'gut-feelings' or heightened senses they experience in response to stressful environments as responsible for saving their lives. Without using these instinctual emotional traits, the death rate during war would increase exponentially.

Future guidelines for drug testing should include stipulations stating that only intermediate points in the signaling cascade can be altered for impermanent periods of time. These changes should also be contingent on thorough examinations of the long-term effects caused by the constant suppression of the Fkbp5 gene. It is far too soon to tell what other effects such treatment would trigger, but this would at least somewhat help maintain the reversibility of a new anti-anxiety drug, and thus circumvent the issue of permanent personality alteration. It would also be useful for the patient if the treatment is followed by the gradual introduction of stimulants for the fear and anxiety responses accompanied by counseling. In this way the individual can learn to deal with the emotions, much the same way an autistic child learns to identify facial expressions and vocal cues with exposure. Permanent or long-term treatment for mental disorders may be appealing, but if used irresponsibly, the personality changes it elicits

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can have damaging effects on society and the human psyche.

References

Attwood, B.K. et al. Neuropsin cleaves EphB2 in the amygdala to control anxiety. Nature: doi:10.1038/nature09938 (April 20, 2011)

Mazumdar, Tulip. "Soldier's 'instinct' saved colleagues from grenade" BBC Newsbeat, Sep 24, 2010

PubMed Health: Drugs and Supplements: Alprazolam.http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0000807/. Revised Nov 1, 2010

The Ethical Ramifications of Creating Neural Progenitor Cells

Alexa Semonche and ??

On April 25th, 2011, a team of scientists from the University of California San Diego, in collaboration with the Scripps Institute, the Gladstone Institute, West China Hospital, and the Korea Research Institute of Bioscience and Biotechnology successfully transdifferentiated fibroblasts removed from mouse embryos into functional and proliferating neuronal progenitor cells (NPCs). These NPCs were then developed into neurons or glial cells. This biotechnology is novel because it bypasses reprogramming of the mouse fibroblasts into induced pluripotent stem cells (iPSCs) before their transdifferentiation into NPCs. The scientific advantages of directly reprogramming mouse fibroblasts into neural progenitors are twofold: first, should this biotechnology prove successful and proliferate, the process of replacing or regenerating cells in diseased or damaged body tissues will be greatly expedited in bypassing an intermediate induced pluripotent stage; second, colonies formed via this new technique yield a significantly greater proportion of cells expressing the desired neuroectodermal markers than colonies formed by inducing iPSCs and then transdifferentiating iPSCs into NPCs.

The methodology for directly reprogramming mouse fibroblasts to neural progenitors closely resembles that for inducing pluripotent stem cell status in somatic cells and then transdifferentiating these induced pluripotent stem cells into neural or glial cells. The crucial, innovative difference between these two techniques occurs when fibroblasts are exposed to either a pluripotent programming medium (Rep-M Pluri) or a neural programming medium (Rep-M Neural). The cell transdifferentiation process begins with a mouse embryonic fibroblast system (MEF). To keep these cells alive in their initial state, they are placed in a reprogramming initiation factor called RemP-Ini.

The neural programming medium Rep-M Neural is then added to the MEF, which induces the generation and proliferation of NPCs. A colony containing hundreds of cells develop and are identified as NPCs by the pronyelocytic lukemia zinc finger, rosette NSC marker, and the neural transcription factor Pax-6 the cells exhibit. The cells in the NPC colony are then isolated and cultured to allow for further differentiation. The resulting colonies yielded various types of neurons, including NeuN, Map2, and GABAergic mature neurons. By day 20, fully differentiated neurons in these colonies exhibited synapsin I, which, when tested, allowed these cells to fire action potentials, establish synaptic connections, and establish excitatory postsynaptic currents. Thus, this novel process allows scientists to bypass the intermediary step of inducing pluripotence in somatic cells before transdifferentiating them to neural progenitors.

Although this new methodology bypasses the use of iPSCs, it does not bypass the bioethical concerns commonly associated with the use of stem cells in research. The University of San Diego team began the cell transdifferentiation process with the same MEF system used in inducing pluripotent stem cells, which do originate from mouse embryos. The MEF system does require the abortion of mouse fetuses and the sacrifice of mouse embryos. It is important to consider this as it violates the notion of nonmaleficence: there is a sacrifice of life necessary to create and sustain this technology. The question, then, is whether the potential health benefits of this research outweigh the harm that is committed in sacrificing these mouse embryos. However, the ethical issue of sacrificing potential lives need not be resolved immediately, but instead diffused. Scientists have already associated with inducing pluripotent stem cell status from adult fibroblasts can be avoided by bypassing this step, which suggests that the use of this technology might result in more biological good than harm in creating the technology in the first place.

Another bioethical issue concerning this technology questions its application to humans. The issue of testing such biotechnology on human patients is inevitable and the risks exposed to the first recipient of these transdifferentiated NPCs must be weighed against the possibility of his meaningful consent as well as the procedure's potential utility for society. However, this issue seems to be largely resolved in the bioethical community since experimental treatments utilizing transplanted neurons to restore normal dopamine function/ levels in Parkinson's patients have already occurred by multiple research institutions. Moreover, this technology promises to be safer than the use of transplanted differentiated iPSCs because the direct reprogramming of fibroblasts into neural progenitors yielded colonies of NPCs, the cells in which almost entirely expressed the desired Pax-6 and Sox-1 neuroectodermal markers as opposed to the NPCs developed from an intermediary iPSC form, which exhibited a more arbitrary array of expression markers. Avoiding the formation of arbitrary markers and transcription factors decreases the chances of further complications, such as cancer, as well as host-rejection possibilities. Thus, the direct reprogramming methodology more accurately controls the type of resulting neurons or glial cells. This unique result may mitigate the risk of developing teratomas or differentiation of iPSCs into undesirable tissue cells. The issue of testing this new biotechnology then requires a much smaller leap of faith than the application of current stem cell therapies, which are already condoned under current bioethical standards. The risk of causing harm to a consenting patient is reduced while the benefits to society are increased, suggesting that bioethically and

pragmatically this technology is a better alternative than stem cell therapies offered today.

Another bioethical issue may arise when considering the implications of implanting artificially developed neurons. Neural tissues are different from other body tissues in that they are responsible for a conscious experience of the world. The electrophysiological, biological (i.e. encoding specific proteins), and morphological properties of neurons interact in neural circuits, which give rise to human emotion, cognition, and consciousness. Considering that neuroscientists remain largely unaware of exactly how certain arrangements of neurons lead to certain experiences, replacing or adding artificially constructed neurons may alter the functioning of the brain in a way that not only impacts the physical function of the brain, but also how the patient perceives and reacts to his or her surroundings. In the case of severely degenerative illnesses such as Huntington's or Parkinson's disease, potential changes in brain functioning may certainly be welcome. However, if altering the natural circuitry of the brain leads to changes in the patient's behavior or personality, then the use of the treatment ought be evaluated in terms of the scientist's obligation to non-maleficence. For example, frontal lobotomies are now a highly stigmatized treatment because while they objectively cured a biological impairment, they often rendered patients emotionless, thereby reducing their quality of life in a serious manner. If this biotechnology does detrimentally impact the patient's quality of life, then it should not become a standard treatment even if it does increase longevity of life.

However, even in the best case scenario, in which there are absolutely no physical side-effects to this treatment, there are profound bioethical issues surrounding a potentially unlimited supply of neural cells. If the scientific community considers the point of a human's death to be the termination of brain functioning,

then the use of directly differentiated neurons may actually prolong a life far past its natural timeframe. Does the doctor's obligation to beneficence obligate him or her to continue a human's life in terms of brain life as long as a new colony of NPCs can be conveniently generated? The answer is no—first, because such technology will differentially advantage the rich. Second, even if the technology quickly becomes accessible to all, the unreasonable continuance of a human life beyond a naturally projected lifespan will only decrease the value to life—if eternity is granted, there is no reason for us to really care about anything in particular. Memories and consciousness as well are precious because there is an acceptance that there are only so moments in this life. In a way, this negatively affects the patient's autonomy because it makes each decision less worthwhile. The implications of this issue are hugely important since the scientists of this article outlining this biotechnology imply that this process of direct differentiation could be a general methodology for transdifferentiation into multipotent cells, which would allow for preservation not only of neural cells, but also of general somatic cellspotentially a whole body rejuvenation method.

A final question is whether the government should subsidize this technology. The answer is yes. First, having a neural disorder/illness is often a morally arbitrary harm—nobody can deserve to have Alzheimer's or Huntington's. We believe the government has the obligation to rectify arbitrary harms to its citizenry. For example, if you meet an unfortunate set of circumstances that force you on the streets, there is a welfare system to ensure that you have a chance to recover and get back into the workplace. Moreover, if we don't obligate the government to subsidize this, then companies can methodology the behind patent transdifferentiation, which could apply not only to neural cells but any kind of somatic cells as well, which would certainly inhibit access of this methodology to patients and other researchers.

Companies like this are government subsidized already, so they shouldn't worry about going bankrupt from having another company swoop in and steal their R+D—at that point, the health concerns of the general public should come first.

References

Kim, Janghwan et. Al, "Direct Reprogramming of Mouse Fibroblasts to Neural Progenitors". Proceedings of the National Academy of Sciences Early Edition (April 25th, 2011). http://www.pnas.org/content/early/2011/04/26/1103113108.full.pdf

Section III: Transplantation

Bone Marrow Transplantation: a viable cure for HIV/AIDS?

Caitlin Burk and Céline Pascheles

In February 2007, an HIV-positive German man received a bone marrow transplant to treat acute myeloid leukemia. About a year later, he relapsed and received a second transplant. Though he had brief bouts with both graft-versus-host disease and leukoencephalopathy, his cancer is currently in remission. As an added bonus, his HIV also appears to have been cured. This apparent cure is due to the genotype of the bone marrow donor: when choosing a source of stem cells, his doctors chose an individual homozygous for a 32 base pair deletion in the chemokine receptor type 5 (CCR5) gene.

HIV is a disease of the immune system; it enters, replicates in, and eventually causes the death of T-cells and other immune cells, slowly depleting the host's defenses until the individual is no longer able to resist what would normally be unremarkable infections. Those strains of HIV that infect certain macrophages and CD4⁺ T-cells do so by recognizing both CD4 and a coreceptor, CCR5, on the surface of these immune cells. After this recognition, HIV is able to enter and begin replicating. A certain frame shift mutation has been identified in humans wherein a deletion of 32 base pairs in the gene causes a nonfunctional receptor to be produced. Individuals homozygous for this mutation (with the $CCR5\Delta32/\Delta32$ genotype) have been shown to be resistant to strains of HIV that depend on CCR5 for their entry.

When the patient received the CCR5Δ32/Δ32 bone marrow transplant, he received hematopoietic stem cells, which give rise to many immune cells, including T-cells. After the transplant, he started making new T-cells from these new stem cells. These new T-cells had non-functional

CCR5, were immune to his HIV, and slowly started reconstituting his immune system. Now most of the patient's T-cells are donor-derived and are at a normal level. In addition, no signs of HIV are detectable. Continued observation of the patient is needed, but it seems that a cure for HIV has been discovered.

A reasonable response to this exciting finding would be: "Wow, a cure for HIV? Why not treat everyone in need?" Theoretically, we could wipe out HIV with this treatment. So why not do it? Despite the excitement and high hopes that this treatment invites, there is one major problem with this solution: there is not enough CCR5 Δ 32/ $\Delta 32$ bone marrow to go around. The CCR5 $\Delta 32$ allele is only found at a frequency of 10% in persons of Northern or Western European decent. That means that only 1% of this already limited population has two copies of the deletion. For example, if we assume that all of Europe is of Northern or Western European descent and we also assume that all of the United States is of Northern or Western European descent, we still only get about 12 million people in the world that have the CCR5 Δ 32/ Δ 32 genotype. However, the latest UNAIDS report on the world HIV/ AIDS burden estimated that there are 33.3 million people in the world living with HIV/AIDS and that 2.6 million new cases are added to this number each year. Therefore, even if this treatment was approved, and every possible donor donated, each person with the needed genotype would need to donate at least twice. Given this major limitation, should this therapy be offered? Could we make it ethical?

With the limited supply of individuals that have this lifesaving genotype, it would be nearly impossible to treat all HIV patients with this new biotechnology. Consequently, the need to decide what patients will receive the treatment will undoubtedly create controversy not only in terms of how best to allocate the minimal available resources, but also in terms of who will have the right and the authority to make such life-determining decisions. Though allocation will be the ultimate stumbling block, we could try to make these decisions easier by maximizing the amount of bone marrow available for transplantation. The steps to increasing the supply would be identifying as many individuals as possible with the CCR5 Δ 32/ Δ 32 genotype and then obtaining their marrow--either by a voluntary or by a compulsory procedure.

The only way to definitively identify all individuals with the appropriate genotype would be to institute mandatory genetic testing for persons likely to have two copies of the mutation. The fact that the allele is found in a population that is both difficult to define and geographically would make dispersed implementing this practice difficult. People "of Northern and Western European descent" are found all over the globe, as evidenced by studies that have found the allele on every continent. Because checking the genealogy of every person or profiling based on race would be time consuming, discriminatory, and/or faulty, the best, and perhaps only, solution might be forcing every person in the world to get genetically tested for this mutation by adding the test to existing prenatal panels. Testing everyone on Earth would be logistically challenging, but would be the best way to find every possible donor. If we were able to overcome the difficulties in implementation, would it be ethical?

Clearly, mandatory genetic testing would spark major concerns, and there are bioethical arguments for and against this measure. On the one hand, forcing a genetic test requires that the patient gives up his or her autonomy. Though the argument can be made that the loss of autonomy

in this case would be less severe because every person in the world would be affected, institutionalizing a loss of autonomy still does not change the fact that autonomy is lost. Indeed, we do see this type of an institutionalized loss of autonomy in the genetic tests our country performs at birth, but this differs in a significant way: we test for genetic diseases at birth in order to allow the families to plan and to begin treatment as soon as possible. The patient's loss of autonomy directly benefits them in the long run. In the proposed case, however, the patient's loss of autonomy would not directly benefit them, but another patient. In fact, the genetic test might even subject the patient to either forced donation or strong pressures to donate.

The issue of who would benefit from forced genetic testing brings up an argument for the measure: the greater good. When an incurable disease infects 33.3 million people spread across every country in the world, how best to deal with the issue becomes less a case-by-case problem, but a global problem. Global problems require global solutions. Therefore, it could be argued that a small loss of autonomy for a few generations is of little importance when weighed against the potential benefit to the world. Once HIV reached a low enough level, mandatory testing could be removed--it would be a temporary sacrifice for a permanent solution. This new biotechnology as a solution to HIV will only be effective as a global cure if there is a sufficient supply of bone marrow. Under the "greater good" argument, it therefore seems reasonable to accept mandatory genetic testing as the best and most efficient way to increase this supply.

But if mandatory genetic testing were approved, what would the conditions of donation be? Would we force every homozygous individual to donate their marrow or would we give them a choice? If we were to institute mandatory testing across the globe, it seems necessary that the outcome is the global elimination of HIV/AIDS.

treatment, however, would be to outpace the number of new cases a year--and that means doing over 2.6 million transplants, or having over 20% of the possible donors donate every year. Given the difficulty of finding HLA matches, the actual number of willing donors would need to be much higher. Because voluntary donation rates are nowhere near 20%--only 2% of Americans are on the national bone marrow donor registry--we would most likely need to institute mandatory donation to reach this goal. Can we force someone with life-saving cells to donate them?

The main factor this question hinges on is the bone marrow donation procedure. If the procedure were simple and painless, answering this issue would be easier, since the arguments against forced donation focus on intangibles like autonomy, which can be fairly easily countered with the greater good. A person being harmed in an intangible matter to help another person in a tangible way is justifiable--there is a gain in overall world health. But if the procedure is complicated or involves physical pain, the issue becomes trickier. Unfortunately, the donation of bone marrow involves a surgery, and with it comes the dangers of anesthesia and post-surgery physical discomfort. In this case, a person is risking physical harm to help another person they may not even know, which is more difficult to justify-- and in fact there is no "net gain" here in terms of health. In order to ensure we had enough supply to meet the global need, however, we would have to seriously consider implementing this measure. Not necessarily. New technologies are available to give GCSF and promote bone marrow stem cell efflux into the blood. Now you can merely take blood and separate the hematopoietic stem cells via FACS and do the transplant via IV.

Even if we are able to increase the number of cells available, we will not have enough to give to every single patient. In light of this reality, we are forced with the bioethical challenge of how

to distribute the limited available resources. Should we develop better techniques to proliferate the stem cells in vitro. How will the resources be allocated and who will be responsible to make such important decisions?

Since HIV-positive individuals and potential donors are spread across the world, the best solution would be to have a globally recognized appointed general body in charge. This group would be composed of competent physicians and researchers who have the needed knowledge to make careful and informed decisions as how best to distribute the limited resources. All information regarding available resources would be sent directly to them, and it will be their responsibility to make allocations accordingly. Only in this way would we be able to ensure a systematic, efficient, and well-organized allocation of resources. The formation of such a committee, however, would be rather difficult, as it would require an international group of physicians and researchers from various countries to gather and collectively agree upon these decisions.

But even if the medical community can come to agreement and acknowledge an appointed general body as the authoritative figure who will decide what patients will receive this novel treatment, we are still left with the question: Who should receive these cells? You could argue that younger patients should be given life-saving treatments first. It seems more just that a young child, who has vet to experience life, get the treatment over an older patient. This argument works well in situations where not receiving a treatment would cause immediate death, but does not apply directly to HIV/AIDS. With HIV/ AIDS, the question of young versus old changes because of the long latent period of the virus. With current antiretroviral therapies, the median survival time of a newly infected patient is about 20 years, and once HIV has progressed to diagnosable AIDS, the average survival time with antiretroviral therapy is only about 5 years.

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A patient would not die tomorrow if he does not receive a transplant, but will die eventually if he does not receive one. It makes sense then, in this case, to first select the sickest patients, as defined by a certain T-cell level and viral RNA load, and then choose the youngest of that group. Because postponing treatment would not cause immediate death, our first priorities are shifted.

While this approach is logical, it fails to take into consideration the feasibility of such a practice. Given the approximate \$100,000 price tag, which would amount to \$3,300,000,000 when applied to all 33 million HIV infected patients, (times 33 million HIV infected people comes to \$3.300.000.000.000- what a price tag?)that comes with this treatment and the concentration of HIV/AIDS in sub-Saharan Africa, it seems rather unlikely that all patients who are qualified to obtain the treatment would be able to afford this therapy. Given this reality, what will become of extremely poor patients, who make up a significant portion of HIV-positive individuals? Will they be deprived of this treatment simply because they cannot afford it? According to the bioethical principle of justice, there is a moral obligation to treat all patients equally. Therefore, not to give a patient treatment simply because of their socio-economic status calls into question the bioethical principle of justice. To limit who could get the treatment based on financial circumstances would be unjust, and can be considered to be both immoral and unethical.

The only way to overcome this hurdle and assure fair allocation, therefore, would be to create a fund that sponsors the cost of the treatment. Only in this way can it be ensured that all those in need get the necessary care, regardless of their financial status. Clearly, a fund that covers the cost of treatment raises the issue of where this money would come from. Since HIV is a global problem that affects the people worldwide, it could be argued, again, that the treatment of HIV needs a global solution: the global community should pay for it. Part of the tax money that each

citizen pays would be donated to this global fund that serves to pay for the treatment. While it could be argued that those without the disease should not fund treatment of those that they do not know, the principle of "the greater good" again offers a counterargument: this would be a chance to get rid of HIV/AIDS and everyone should sacrifice for a short time to rid our planet of what has become a serious epidemic. In order to eradicate AIDS, a global force is needed. Only in this way could we collectively combat the financial obstacle that this new biotechnology presents.

Clearly, the implementations of the above solutions are very challenging, if not impossible. For CCR5 Δ 32/ Δ 32 bone marrow transplantation to be used fairly and bioethically as a cure for HIV, all qualified donors would need to be identified through mandatory genetic testing, all would need to donate, a governing body would need to distribute the resources, and all expenses would need to be paid by a global fund. These are measures that would most likely never be accepted across the world. Additionally, here we have only looked at a few issues surrounding the treatment. Among the others are: the risk of complications (the Berlin patient had two potentially fatal reactions), quality of life during the latent period of HIV versus quality of life after a bone marrow transplant, replacing lifelong antivirals with life-long immunosuppressants, the fact that this treatment only cures M5 HIV and not X4 HIV, and the increased susceptibility to West Nile virus seen in patients with the CCR5 Δ 32/ Δ 32 genotype. Each of these concerns would have its own issues, and require additional measures to make implementation of the treatment ethically sound. It seems from this, then, that using this treatment in an ethical way would require too many difficult decisions and unpalatable solutions. We conclude then, that this new technology should not be used, as any use would be contrary to good ethical practice.

Some might argue that this is a non-solution, that this argument takes the easy way out in suggesting that this new, ethically challenging treatment should not be used. We would say, then, that the real solution is finding a new way to look at this biotechnology. Instead of viewing this paper as saving "a bone marrow transplant can cure HIV" and immediately using it in a clinical setting, we should use the scientific knowledge that this finding has revealed and appreciate the implication it has to offer for future research. Viewed this way, this paper says "HIV patients can be cured if expression of CCR5 on T-cells is repressed," and points the way towards further attempts to develop a cure for HIV infection. As Jay A. Levy suggested in an editorial accompanying the first report of this new technology, the revelation that changing CCR5 expression can potentially cure HIV hints at possible treatments using small interfering RNAs, antisense RNA, or ribozymes. It also suggests that we could design stem cells with the CCR5 deletion, either using embryonic cells or induced pluripotent cells. Though each of these other solutions would come with its own bioethical issues, they probably would not require such extreme measures as the ones suggested for the bone marrow transplant.

Indeed, science is progressing at an increasingly fast pace and exciting breakthroughs in biotechnology are being made. But instead of being so quick to apply these biotechnologies in a clinical setting, we should shift our focus to analyzing how the implications of these new biotechnologies can be used in future approaches to solve the problems they address. It is important that we be cautious about emerging biotechnologies and carefully asses their bioethical implications before actually using them in practice.

References

Allers K, Hütter G, Hofmann J, et al. Evidence for the cure of HIV infection by CCR5Δ32/Δ32 stem cell transplantation. Blood 2011;117:2791-9.

Clevland Clinic. The Bone Marrow Harvest Procedure. 2009. http://my.clevelandclinic.org/ services/
Bone_Marrow_Transplantation/
hic_The_Bone_Marrow_Harvest_Procedure.aspx.
Retrieved 26 April 2011.

Deng H, Liu R, Ellmeier W, et al. Identification of a major co-receptor for primary isolates of HIV-1. Nature 1996;381:661-6.

Galvani A, Novembre J. The evolutionary history of the CCR5-Δ32 HIV-resistance mutation. Microbes Infect 2005;7:302-9.

Glass WG, McDermott DH, Lim JK. CCR5 deficiency increases risk of symptomatic West Nile virus infection. J Exp Med 2006;203:35-40.

Hütter G, Nowak D, Mossner M, et al. Long Term Control of HIV by CCR5 Delta32/Delta32 Stem-Cell Transplantation. N Engl J Med 2009:360:692-8.

Knoll B, Lassman B, Temesgen Z. Current status of HIV infection: a review for non-HIV treating physicians. Int J Dermatol 2007;46:1219-28.

Levy JA. Not an HIV Cure, but Encouraging New Directions. N Engl J Med 2009;360:724-5.

Liu R, Paxton WA, Choe S, et al. Homozygous defect in HIV-1 coreceptor accounts for

resistance of some multiply-exposed individuals to HIV-1 infection. Cell 1996;86:367-77.

Martinson JJ, Chapman NH, Rees DC, Liu Y-T, Clegg J. Global distribution of the CCR5 gene 32-basepair deletion. Nat Genet 1997;16:100-3.

Majmunder K. Let's compensate bone marrow donors. USA Today, 11 February 2011. http://www.usatoday.com/news/opinion/forum/2011-02-09-majumder11 st N.htm>. Retrieved 24 April 2011.

National Bone Marrow Transplant Link. Resource Guide for Bone Marrow/Stem Cell Transplant. 2010. http://www.nbmtlink.org/resources_support/rg/rg_costs.htm>. Retrieved 26 April 2011.

UNAIDS. Global Report: UNAIDS Report on the Global AIDS Epidemic 2010. 23 November 2010. http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/20101123_globalreport_en.pdf>. Retrieved 23 April 2011.

Transplanted Identity

Pankil Desai and Jeff Yang

Organ transplants, due to their life-saving capacity as well as the complexity of the procedure, are currently among the most high-profile surgeries performed throughout the world. Among the newest techniques is facial allograft transplantation (FAT), which involves composite tissue allotransplantation (CTA) of nonparenchymatous tissues (skin, muscle, tendons, bones, etc.) to reconstruct specific body parts like the face. Since the first facial transplantation was performed in 2005, cosmetic flesh and skin grafts of the face have proven to be both a commercial craze as well as a point of ethical contention. Since then, thirteen partial face transplants have been carried out, primarily as a way to repair and restore nerve function to facial tissue damaged by scarring, burns, disease, or birth defects which were not possible using previous conventional technologies. However, the first full face transplant, which was performed on 25year-old Dallas Weins at Brigham and Women's Hospital in Boston, did not take place until March, 2011, with the second taking place less than a month later. Both of these operations aimed to repair and replace tissue damaged due to severe burns and shocks sustained in traumatic accidents, and have since restored much of the sensation and animation in the previously dead scar tissue on and around the patient's face.

Unlike more conventional organ transplants, such as the liver or kidney, skin transplants often have different risks and benefits associated with it. First and foremost, it is not a medical procedure that is essential or life sustaining; rather, it is a cosmetic operation which has great capacity to improve the quality of life for those who receive such reconstructive surgeries. However, FAT procedures are extremely complicated because of the abundance of nerve connections and small capillaries that run throughout the face, requiring a number of delicate and expensive

microsurgeries. Each of these operations runs the significant risk of bacterial infection, and the risk of immuno-rejection often requires a lifetime of immunosuppressant drugs and treatments, which puts the patient at further risk for a variety of infectious diseases. This begs the question, "are the benefits of cosmetic facial transplants worth risking the patient's life?"

In addition to the increased danger of long-term failure and infection, the possibility of full-face transplantation raises another ethical problem that isn't addressed by many other organ transplants: the issue of identity. In a society where identity is often determined through appearances and visual cues, disfigurement may lead to prejudice, discrimination, stereotyping, and social isolation. Facial transplantation offers an opportunity to repair one's self-image as well as restore physical and neurological function in addition to just reconstructing the face. On the other hand, the ability to essentially change one's entire image can be an unnerving prospect if taken to the extreme. Considerations have to be made not only for the patient, but also for his or her family, friends, and community. For example, how will a spouse respond to an unfamiliar face? His or her children? An employer? On the other hand, the potential to restore familiar characteristics to a disfigured face could have an overwhelmingly positive effect. Furthermore, the identity of the donor also needs to be addressed. Organ donors may be willing to give up a lung, heart, or kidney after death, but would they be willing to posthumously relinquish significant portions of their bone, muscle, and skin toward a total face transplant? Because of the possibility of physical mutilation that this brings to a potential organ donor, should the donor's family and friends also be considered in the decision?

While clinical FAT can allow a burn or trauma patient to regain some of their former identity

and life, what if facial transplantation becomes another commercially marketable form of plastic surgery? Plastic surgery, a heavily demanded medical procedure in the United States, is already an enormous source of fuel for the vanity of the rich. Instead of altering individual body parts, what if an individual could casually change his or her entire face? In this case, the ethical implication is the potential breakdown and trivialization of identity. If one can simply change his or her physical appearance at will with a quick operation, what does identity mean? With this possibility for commercialization also comes the ethical consideration regarding the potential criminal and black-market application of FAT procedures. With total facial transplants, for example, it would be much easier for criminals and con artists to assume and steal the identities of ordinary citizens. Moreover, if used by criminals to elude the law by constantly altering their physical appearances, what is to stop law enforcement agencies to employ the same strategies? How far could this strategy be allowed to go, and how could we stop it if the consequences become unethical? Without a series of checks and balances, this chameleon effect could easily spiral out of control.

Because the issue of total facial transplantation involves the social and individual identities of both the donor and recipient, as well as the surrounding community, a possible solution to the ethics regarding total face transplants is to require a series of informed consents and recommendations from the physicians, the patient, and his or her family. Because of the potential physiological and psychological risks of FAT procedures, a comprehensive discussion of the both the medical and social implications should be conducted between the physician and recipient to weigh the benefits and risks of the procedure on an individual basis. Furthermore, there needs to be strict regulation and limitations surrounding the extent to which the appearance of the patient can be altered. Facial transplants should be limited to those who have experienced

major disfigurement, and to whom a total face transplant would offer a chance to restore both facial function and a semblance of their former lives. By no means should such a procedure be commercialized, due to both the serious medical risks and the social implications of "mass-producing" endless cycles of appearance and identity altering facial transplantations.

References

Associated Press. "Boston hospital performs 2nd full-face transplant." Forbes.com. 26 April 2011. http://www.forbes.com/feeds/ap/2011/04/26/general-us-face-transplant 8434864.html>.

Barclay, Laurie, MD. "First Face Transplant Raises Ethical Issues." Medscape Medical News. 2005. http://www.medscape.com/viewarticle/520031.

Freeman, Michael, and Pauline Abou Jaodé. "Clinical Ethics: Justifying Surgery's Last Taboo: The ethics of face transplants." Journal of Medical Ethics. 23 June 2006. http://jme.bmj.com/content/33/2/76.full.

Commercialization of Organ Transplantation

Authors??

According to the US department of Health and Human Services, as of March 6, 2011, 110,568 candidates are waiting for an organ transplant in the United States yet only 13,251 organ donations took place in 2010. Every ten minutes, a person is added to the national organ transplant waiting list and 18 people die every day due to the shortage of organ donations in the United States. These shocking statistics signaling high demand and low rates of organ donation lead us to question whether the United States should legalize organ selling and whether it is ethical to do so.

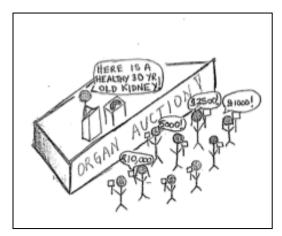
Since 1984, accepting or offering money in exchange for human organs is punishable by fine or imprisonment as stipulated by the National Organ Transplantation Act (NOTA). The act was designed to prevent the wealthy from having an advantage in procuring organs. However, the current method of organ distribution severely limits the number of patients on the transplant list that actually receive an organ. The World Health Organization supports acts like NOTA, suggesting that countries should continue to actively, "take measures to protect the poorest and vulnerable groups from 'transplant tourism' and the sale of tissues and organs." "Transplant tourism" refers to the methods wealthy patients may employ to acquire organs, such as going to another country to purchase an organ from a person in need of money. However, in addition to preventing the wealthy from receiving organs preferentially, there are several other reasons why sale of human organs is frowned upon.

Opponents of the sale of human organs believe that exchange of money for organs reduces the human body to a commodity with a price tag. This reduction of value can be degrading to those who participate in the transaction and the use of money to convince people to donate could be perceived as exploitative. The United States senate expressed these views in their report accompanying the passage of NOTA; that "human body parts should not be viewed as commodities."

Although some argue that the sale of human organs may lead to serious ethical transgressions, banning this practice might incur more moral harms overall. Prohibiting people from doing what they desire with their bodies violates the bioethics principle of autonomy. The principle stipulates, "The patient has the capacity to act intentionally, with understanding, and without controlling influences that would mitigate against a free and voluntary act." According to this principle, if a patient is determined to have his kidney removed and sell it then he should be able to do it. By preventing him from doing so, the government is violating the principle of autonomy.

Economics professor Ninos Malek of San Jose State University argues that the benefit of allowing people to give or receive money in exchange for an organ is quite simply that: "...money is the catalyst that relieves the shortage." He reasons that the exchange is mutually beneficial; the donor wants money and is willing to give up an organ while the recipient wants the organ and is

willing to give up money. From an economic standpoint, these monetary transactions would increase the number of donations, which should be followed by a decrease in their price. By this logic, the issue of advantaging the wealthy in acquiring organs should be negated because the economically disadvantaged may even benefit from monetary compensation and organ prices would not skyrocket.



Moreover, there are several human products that can currently be sold legally in the United States, such as blood plasma, human hair, egg cells, and sperm cells. Sale of these human cells and tissues is not prohibited, frowned upon, or seen as devaluing the human body; so why should the sale of an organ devalue the human body? The limitations imposed on organ sales have only served to push those who are desperate to purchase an organ towards the black market, where prices for organs are exorbitant and the removal, transport, and transplantation of organs is not well monitored. Legalization and acceptance of the sale of organs would not only increase the supply of organs, but it would allow the government and health professionals to

ensure that the organs are handled properly and that they are only taken from eligible, consenting donors. Clearly, the benefits of allowing the sale of organs greatly outweigh its detriments.

Furthermore, even if the government wishes to limit exploitation of organ donors by the wealthy through the prevention of the sale of organs, those who are capable will always find another way to gain an advantage. For example, controversy arose when Apple CEO Steve Jobs flew to Tennessee to receive a liver transplant. There was concern over the fact that Jobs received his liver within a fraction of the average waiting time. He also had the resources to fly to another state and receive the liver transplant. Due to his economic status, he was able to more easily complete all the required appointments and consultations with surgeons, social workers, and psychologists in order to receive the new liver.

Kidneys and livers are in the highest demand from live donors and studies show that donors can live perfectly healthy lives with just one kidney, while livers can almost fully regenerate a donated segment. Furthermore, in a study by Schweda et al, 2009, it was found that organ recipients favored compensation of donors because they felt that "the donors' generosity and dedication deserve to be acknowledged and counterbalance." Providing compensation would assist deceased donors in covering the costs of their death and compensation of live donors would allow for a feeling of reciprocity between the donor and recipient. Considering the benefits of creating a legalized and regulated organ market, the U.S. government should reconsider its 32 *spring 2012*

policy about organ selling as it has the potential to save many lives and many ethical concerns can be alleviated with proper regulation.

References

- "Bioethic Tools: Principles of Bioethics." UW
 Departments Web Server. Web. 09 Mar. 2011.
 http://depts.washington.edu/bioethx/tools/princpl.html>.
- M. Schweda, S. Wohlke, S. Schicktanz,
 Understanding Public Skepticism Toward Organ
 Donation and Its Commercialization: The
 Important Role of Reciprocity, Transplantation
 Proceedings, Volume 41, Issue 6, July-August
 2009, Pages 2509-2511, http://www.sciencedirect.com/science/article/B6VJ0-4X372K8-55/2/b2a33f0c5a0
 6193820bcfb16dbb0cde0>
- Malek, Ninos P. "Sell Your Kidney, Make a Profit -Ninos P. Malek - Mises Daily." Ludwig Von Mises Institute - Homepage. Web. 07 Mar. 2011. http://mises.org/daily/660>.
- "Organdonor.gov | Statistics and Facts." Welcome to Organdonor.gov | Register Today as an Organ Donor. Web. 06 Mar. 2011. http://www.organdonor.gov/aboutStatsFacts.asp.
- S. REP. NO. 382, 98th Cong., 2nd Sess. 2 (1984) at 17.
- Satel, Sally. "Steve Jobs' Liver Forbes.com." Information for the World's
 Business Leaders Forbes.com. 21 Jan. 2009.
 Web. 09 Mar. 2011. http://www.forbes.com/2009/06/21/steve-jobs-liver-national-organ-transplant-act-opinions-contributors-sally-satel.html>.
- Tabarrok, Alex. "Tackling the Organ Shortage -WSJ.com." Business News & Financial News -The Wall Street Journal - Wsj.com. Web. 06 Mar. 2011. http://online.wsj.com/article/SB1000142405274870348100457464623327299 0474.html>.
- "WHO | Human Organ and Tissue Transplantation." World Health Organization. Web. 07 Mar. 2011. http://www.who.int/ethics/topics/human_transplant/en/>.

Section IV: Autonomy and Human Dignity

Genetic Testing and the Limits of Parental Rights

Authors?

If you could find out how you would die, would you want to know? With the rise of personal genome testing, this question no longer dwells solely in the realm of science fiction. For several years, biotech companies such as 23 and Me, Navigenics and deCODEMe have claimed the ability to predict traits like hair color, short-term memory functionality, risk of nicotine addiction, and even the potential for spirituality—all based on our DNA. Though destiny cannot be predicted with absolute certainty, scientists can now provide parents with an infant's chances of ultimately developing a host of serious diseases. Several companies that provide personal genome testing have claimed the ability to report the chances that a child will develop breast cancer, heart disease, and other life-threatening disorders. Our genetic code is just as personal as our innermost desires or foremost predilections. Should we not have the privilege of choosing whom its features can be divulged to? Parents can be understandably curious about the future health risks their children will face, but in a society where privacy is touted as an individual's right, they cannot justify subjugating their children's entitlement to do as they please with private genetic information.

There is no doubt that parents can, and must, have some control over their child's medical decisions until they have reached adulthood. After all, what 8-year-old would voluntarily receive a vaccination, or have their tonsils removed? The difference, however, lies in the necessity of the medical practice. Without a vaccination, a child could potentially contract a life-threatening illness. That is a valid concern, and should be handled accordingly by parents. However, of the diseases that can be predicted

by genetic testing, none can be completely cured simply by early detection. Symptoms associated with cystic fibrosis, sickle cell anemia, and other diseases can be alleviated, but they cannot be cured. So the question becomes: is the slight advantage conferred by early detection of these diseases worth both the infringement of rights and the added stress caused by that knowledge?

The answer to this question should first evaluate the legal implications of genetic testing. One of the Hippocratic Oath's most well-known agreements declares, "Whatever, in connection with my professional service, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret." Commonly referred to as doctor-patient privilege, this oath confers the right of medical confidentiality to each individual a doctor treats. All individuals, from the day they are born, are granted this right by way of common law. When a parent requests a physician, or any licensed professional to divulge the contents of their child's genetic makeup, they are breaching that agreement. Yes, it would be acceptable for a parent or guardian to know the details surrounding their child's wellbeing before making a decision pertaining to medical treatment, since this knowledge is essential to making an informed decision. But what makes this situation unique is the fact that the disorders that can be found using genetic testing will generally not manifest themselves until after a state of maturity has been reached. Under normal circumstances, the child—at this point, already an adult-would at least have the option of not disclosing his or her condition to the parents. Premature genetic testing removes this choice.

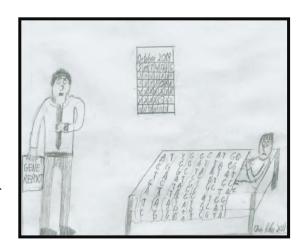
Another issue to consider is the potentially disturbing nature of the information revealed by genetic testing. To put into perspective the added stress conferred by this testing, consider a hypothetical case in which a mother is informed that her son is especially prone to developing early-onset Alzheimer's disease. The doctor informs her that there is no cure, no treatment for this illness. There is little to be done by the mother, apart from agonizing over the eventual degradation of her son's mental faculties. She is also burdened by the decision over informing her son of his fate. Moreover, what right does she have to possess this information? Parents generally want what's best for their children. But it should also be considered whether knowing the details of their progeny's future health concerns is actually a beneficial piece of information. In this case, the mother is not only forced to deal with her frustrations during a period reserved for quality time with her son, but she is also plagued by the paralysis of having no mechanism for solving the problem.

Like most bioethical debates, this dilemma will only reach a veritable conclusion after compromises from those in favor and opposed to the genetic testing of children. What must be agreed upon, however, is that the eventual solution should be evaluated solely on the basis of how it affects the child. The parents should serve entirely as auxiliary characters in this dynamic. Because genetic testing can effectively identify certain diseases that manifest themselves early in development, parents and physicians should be able to work together to ensure the health of a child. However, this sacred trust between child and guardian should not be abused in favor of a fishing expedition into the child's destiny. The second a parent makes decisions based on the speculative circumstances of a child's future, he is no longer acting as a responsible parent. Many arguments in this debate come in the form of a double-edged

sword, and the greatest peril is the barely cognizant child becoming a victim to either.

References

Health Reports: Complete List," <u>23andMe</u>, 2011, 7 March 2011 https://www.23andme.com/health/all/



Let's hurry it up, Billy. This says you were supposed to get over the chicken pox two weeks ago.

How Young Is Too Young?: A Child's Right to Information

Authors?

After being diagnosed with AIDS and having spent the last two years confined to a hospital bed, nine-year-old Rachel's doctors concluded that she had less than six months left to live. Her grandmother, as Rachel's legal guardian, requested that Rachel not to be told about the severity of her disease and instead be told that she has kidney failure. The doctors, uncomfortable with this request, were torn between the wish to respect the decision of her grandmother and to tell Rachel the truth about her disease, not knowing how to comprise the harsh reality of the situation with her status as a minor. This dilemma begs the question of how much information to disclose to terminally ill pediatric patients: how old is "old enough to know"? Should doctors tell their pediatric patients that they are going to die soon?

Providing pediatric patients with information about their deaths only seems meaningful if they have an understanding of what death is. Initial studies, such as those done by Mary Nagia in 1948, attempted to place a timeline on children's understanding of death. Her studies demonstrate three stages of understanding--the first usually extends from ages one to four, the second from five to nine, and the third from ten and thereafter. Of particular interest are children falling under the late second and third stages, in which they become aware of the finality of death. However, this does not necessarily imply an adult understanding of death and in her 1966 article "Maturation of Concepts of Death," Adah Maurer suggests that a child's understanding is a combination of cognitive development and personal experiences. The depth of the conception of death is directly correlated with the child's interactions with it, such as the death of a pet or a relative.

The development of a conception of death was

the subject of a study conducted in Sweden from 1992-1997, in which parents of children who had passed away from a terminal disease were surveyed on their perceptions of their children's awareness of their own deaths. The average age of death of the children in this study was around 13.05 years old, and of the 449 children who had passed away from a terminal disease during this time, only 37% were told of their impending deaths. However, of the parents who did not tell their children about their imminent deaths, 54% felt that their children somehow knew or suspected the severity of their diseases. A child's comprehension of death might grow with age, but it also varies greatly with personal experience. Having exposure to death through the passing of a family member at an early age contributes immensely to a child's grasp of what it means to die. Of the children who were told of their deaths, 73% of them had a direct death in their families. The other 46% of children who were not told of their imminent deaths and with no suspicion of it probably did not think about the severity of their disease or question the possibility of death. Death was a more distant and foreign concept for this group, and the children were probably too young or underexposed to consider it in relation to themselves.

The almost bi-symmetric split in the awareness of children shows that the knowledge of death varies per child, and there should be no general rule for disclosing information to terminally ill pediatric patients. Instead, the child's level of mature and capacity for understanding death should constitute a variable in a doctor's decision to disclose the truth. For instance, if the patient directly asks if she is going to die, she should be told the truth, as the question implies a certain level of maturity and grasp of her situation. The parent or guardian's wishes should be respected but not taken as final authority because when

children are concerned, the principle of beneficence should carry greater weight than that of individual mandate.

In the case of Rachel, her doctors decided to respect her grandmother's decision and did not tell her of her imminent death. She died a couple of months later, comfortably at home with her grandmother.

References

Kreicberg, U., Valdimarsdóttir, U., Onelö, E., Henter, J-I., Steineck, G. "Talking about Death with Children Who Have Severe Malignant Disease." *N. Engl. J Med.*, 351: 12, 1175-1186, 2004.

Maurer, Adah. "Maturation of Concepts of Death." *Br J Med Psychol.*, 39:35–4, 1966.

Nagy, Maria. "The Child's View of Death." In Herman Feifel ed., *The Meaning of Death.* New York: McGraw-Hill, 1959.



Source: Patrick Hardin, http://www.cartoonstock.com

Dying with Dignity: Our ethical right, or just an easy way out? Authors?

The Sundance Film Festival, held in Park City, Utah, showcases films from directors and producers worldwide, introducing viewers to new film techniques and challenging their personal beliefs. One of this year's Festival submissions renewed a medical debate that has persisted over the past few decades. Its subject matter dealt with physician assisted suicide, or to put it more bluntly, physician assisted death. Peter Richardson, with assistance from HBO, directed "How to Die in Oregon", a film that chronicles the end of Cody Curtis's life as she copes with terminal cancer and examines the emotional toll of her illness on her family. The film even features a scene where a man dies on camera.

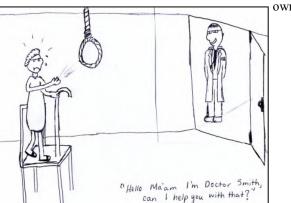
Needless to say, audiences received the documentary with tepid reviews. The intimate view of personal struggle quickly generated questions about the living life in pain or prematurely ending life with dignity.

In 1997, Oregon voted to institute the Dying with Dignity Act. Under this statute, Oregonians diagnosed with terminal diseases and expected to die within six months could apply to participate in physician assisted death (PAS). Unlike most conceptions of PAS, Oregon's version consists of a doctor prescribing a lethal combination of drugs that the patient

administers to themselves. As such, the patient receives safe, effective medication that peacefully ends their life. But who has the final say in matters of life and death: doctor or patient?

American Medical Association codes from 1961 fail to address patient rights. They designate the doctor as quasi-parent who exercises control in the patient's best interest and the patient as incapable of making wise medical decisions. In recent decades, many involved in medical ethics

questioned the paternalism in doctor-patient relationships. It is believed the "doctor's duty of beneficence may conflict with the principle of respect for patient autonomy"("Doctors and Patients"). In Models for Ethical Medicine in a Revolutionary Age, Robert Veatch discusses various models representing the patient-physician relationship. One example, known as the Contractual Model, involves "true sharing of ethical authority and responsibility" where "physicians recognize that patients must maintain freedom of control over their own lives when significant choices are to be made" (Veatch). This model holds the doctor's rights and the patient's rights as equally important. As such, the decision to undergo PAS is as much the patient's



choice as it is the doctor's choice to comply with it.

Though Dying with Dignity allows PAS patients to administer the lethal drug themselves, in most instances, patients waive this right the physicians, who then end their patients' lives. Murder is taken to be unanimously reprehensible and immoral, but does could PAS qualify as murder? It is important to distinguish whether society considers killing to be wrong because it ends a person's life or because of the method or motive behind killing. If the patient has the motive to die, would that justify a physician

sustaining medical treatment may not properly be viewed as an attempt to commit suicide." The Court further justified the ascertainment that PAS is not synonymous with suicide, saying, "people who refuse life-sustaining medical treatment may not harbor a specific intent to die, rather, they may fervently wish to live, but to do so free of unwanted medical technology, surgery, or drugs, and without protracted suffering". In other words, these patients who choose their own death are not doing so lightly, it is often a choice of death or continued suffering for themselves and their loved ones. They may choose PAS as an opportunity to be free from their suffering.

In a few states, including Ohio and Utah, the law permits death-row inmates to choose their method of execution. From Ronnie Lee Gardner's firing squad to John Byrd Jr.'s electric chair, convicted individuals can choose a respectable, painless method of death. If hardened criminals can choose how they die, why not a mother-of-two, diagnosed with Huntington's, or a 40-year-old husband with an inoperable, malignant brain tumor? Few realize this, but terminal patients and death row inmates have a lot in common. Both know they will die and possess no means to prevent this. Moreover, while the inmate's prison consists of bricks and mortar, the patient's prison consists of blood, flesh, and failing organs. Despite these striking similarities, the general public, perhaps hypocritically, condemns the inmate to death while striving to keep the patient alive.

Realizing discrepancies in this logic, Dr. Henrik Lerner from the Center of Ethics at Linköping University polled 2421 Swedish veterinary surgeons about PAS. Nearly 75% responded in favor of PAS. Similarly, 72% of the general public but only 35% of physicians agreed with PAS (Lerner). Lerner hypothesizes that veterinarians find comfort in assisted death because they liken the situation of a suffering family member to the suffering of a family pet - a quasi-family member. When a pet is diagnosed

with a terminal cancer or a degenerative disease, they recommend euthanasia instead of extending the creature's life. The animal's quality of life decreases drastically as they lose control of their bodily functions. The same assertion can be extended to humans; we can extend pain when we extend their lives. Since veterinarians euthanize animals regularly, they understand that euthanasia protects the patient from prolonged pain that can be more debilitating than dying.

Death is always the last resort and supporting PAS is not synonymous with supporting suicide. When patients choose PAS, they often feel that they have no alternative and that prolonged life would be less meaningful due to their suffering. Therefore, the ability to allow someone to die can serve as the best act of mercy available to a physician.

References

"Doctors and Patients." Biomedical Ethics. Web. 07 Mar. 2011. http://www.nvcc.edu/home/aaoudjit/docpat.htm.

Lerner, Henrik. "Veterinary Surgeons' Attitudes towards Physician-assisted Suicide: an Empirical Study of Swedish Experts on Euthanasia." Journal of Medical Ethics 36th ser. 10.11 (2010). Print.

Veatch, Robert. "Death and Dying." Medical Ethics. 377-Onwards. Print.

Veatch, Robert. "Models for Ethical Medicine in a Revolutionary Age." The Patient-Physician Relation. 1 -16. Print.

1985. NJ Supreme Court Case. Claire Conroy.

Eugenic Sterilization: How Many Generations is Enough? Authors?

"Three generations of imbeciles are enough," said Supreme Court Chief Justice Oliver Wendell Holmes, Jr. after a 1927 ruling whereby a "feebleminded" woman who gave birth to a "feebleminded" child was to be forcibly sterilized (Cincinnati). In this infamous case of Buck v. Bell, the medical profession determined that Carrie Buck suffered from hereditary "feeblemindedness." and the courts decided that her future offspring would be "socially inadequate." Buck became the first woman to be involuntarily sterilized in Virginia and this case set a troubling precedent for the development of programs supporting eugenic sterilization. Under these programs, an estimated 65,000 Americans were sterilized involuntarily.

The term 'negative eugenics' refers to methods for the eradication of undesirable elements of society. Sterilization has been integral to this population control system. In 1907, Harry Laughlin crafted the "eugenics sterilization law," which was eventually adopted in over 30 states. "Feebleminded" people who received low scores on an IQ test were sterilized along with homeless persons, orphans, epileptics, the blind, and the deaf. This model was later adopted by Nazi Germany to sterilize over 350,000 "feebleminded" Germans.

More than 80 years after Buck vs. Bell, a similar case has emerged in the UK where the mother of a mentally disabled woman is proposing that her daughter be sterilized. The mentally disabled woman already has one child currently cared for by her mother and is pregnant with another. These two cases raise the question, should eugenic sterilization be practiced to alleviate society of children with "undesirable" traits or adults providing inadequate parental care if they are demonstrated to create unreasonable burdens for others?

Carrie Buck was deemed an "inadequate parent" in court. If a mentally disabled individual is without a dependable partner, should we strip them of their right to reproduce and should an outside party possess their right to decide? Proponents of eugenic sterilization argue that they should, since the responsibility of caring for the child would likely fall on society or a guardian due to the parent's limitations. The economic benefits for proximal family members and the government are apparent—if a parent is unable to raise a child, perhaps the responsibility to do so should not carry over to others. Judge Holmes voiced his support for involuntary sterilization, stating that it could be performed "without detriment to general health" and instead of "sap[ping] the strength of the state for these lesser sacrifices... her welfare and that of society will be promoted by her sterilization" (Cincinnati). The argument here is that the future interests of an unborn child and society at large should be put above that of the parent, as the child would be disadvantaged without receiving proper care.

While sterilization is not physically dangerous, it is an infringement upon human rights. Taking away one's right to reproduce due to a mental disability obligates us to consider the justifications for such a decision. To What extent will a mental disability will be judged to result in unfit parenting? Do the mentally disabled still have the right to a family? And if a mentally disabled person is not sexually active, should they still be sterilized? In Buck vs. Bell, it was revealed that Carrie Buck had been raped. If Carrie had not been raped, she might have never carried a child, in which case the standard justifications for sterilization fall flat. With such subjective cases and blurred justifications, it is difficult to make the case that all mentally disabled people should be sterilized, despite possible socio-economic benefits to society.

fects, or HIV due to the mother's addition as well in society. as prevent children from being born into a negato society...

habilitation and recovery. Preventing addicts from not. reproducing does not tackle the underlying issue of their addiction, and is essentially a form of References negative eugenics. Sterilization of both the mentally disabled and addicts walks a thin line between pursuing society's best interests and ostracizing those who do not fit into society's ideals.

The reality of sterilization, especially for women, is that it is a permanent, life-changing decision. In our pursuit to protect the rights of unborn children, we cannot violate the rights of existing humans. In the UK case mentioned above, the court stated a need to prove that a less invasive method of birth control could not be used to the same end (NPR). Long-term reversible methods of birth control such as intrauterine devices (IUDs) are a

less severe option, especially for drug addicts While the mentally disabled have been targets of who have the potential to change their lifestyles. eugenic sterilization for more than a century, drug For addicts, this decision should be made with addicts are now targets for sterilization by a char- counseling rather than with the motivation of ity group known as "Project Prevention". Project money to buy more drugs. While the option of Prevention offers \$300 to drug addicts to undergo long-term birth control is less radical than sterilisterilization or long-term birth control. Over zation, it is important to consider whether there is 3,000 addicts have participated, most of them sufficient justification for this route in each spebeing women and about 40% opting for steriliza- cific case, and if so, whether the decision is for tion (Adams). This program aims to prevent the the interest of the person and potential offspring birth of children with drug addictions, birth de- rather than to eliminate certain groups of people

tive home environment. It is evident that this pro- We must recognize the danger that sterilization of gram could help break the hereditary cycle of specific people can transform into the genetic addiction. Like the sterilization of the mentally weeding of those who have "undesirable" traits. disabled, this program aims to look out for the This concept has been warped to rationalize rights of the unborn children and for the benefits events that occurred in the Southern US and Nazi Germany, leading to harsh discrimination against African Americans and the Jewish among others, The controversy surrounding Project Prevention eventually resulting in the holocaust under Nazi is that addicts may be incapable of making an Germany. Ultimately, we must define an ethical informed decision regarding their reproductive line at which human rights must be respected for futures, especially when most of them live in pov- all people despite the cost to society. As scholar erty and may feel coerced by monetary rewards. Stephen Jay Gould stated regarding the outcome Thus, this program could very well force people of Buck vs. Bell, "Can one measure the pain of a to forfeit their rights to reproduce. Additionally, single dream unfulfilled, the hope of a defenseless this program assumes that addicts will remain woman snatched by public power in the name of addicts when there is, of course, potential for re- an ideology advanced to purify a race?" We can-

Adams, William Lee. "Sterilize for Cash: Paying Drug Addicts to Not Have Kids - TIME." Breaking News, Analysis, Politics, Blogs, News Photos, Video, Tech Reviews - TIME.com. Time, 17 Apr. 2010. Web. 07 Mar. 2011. http://www.time.com/time/health/article/

0,8599,1981916,00.html>.

"Buck vs. Bell Trial." EugenicsArchive.org. Web. 07 Mar. 2011. http://www.eugenicsarchive.org/html/

eugenics /static/themes/39.html>

Cincinnati, Noah. "A Weapon of Eugenics: Sterilization as a Means to Better the Race." 16 Mar. 2005. Web. 07 Mar. 2007. http://www.umw.edu/

hisa/resources/Student%20Projects/Cincinnati/

Cincinnati, Noah. "The Buck v. Bell Decision: The Supreme Court Upholds Forced Sterilization." 16 Mar. 2005. Web. 07 Mar. 2011. http://www.umw.edu/hisa/resources/Student%20Projects/Cincinnati/students.umw.edu/_ncinc5ce/buckvbell.html

"Eugenics in America: Sterilization." *Educator Resources* | *Facing History and Ourselves*. 2011. Web. 07 Mar. 2011. http://www.facinghistory

campus.org/campus/ rm.nsf/0/378157EF2F49B448852570360070E6F5>.

"The Sterilization of America: A Cautionary History." *Center for Individual Freedom.* 17 May 2002. Web. 7 Mar. 2011. http://www.cfif.org/htdocs/freedom line/current/in our opinion/un sterile past.html

"UK Court Mulls Sterilizing Mentally Disabled Woman: NPR." NPR: National Public Radio: News & Analysis, World, US, Music & Arts. 15 Feb. 2011. Web. 05 Mar. 2011. http://www.npr.org

/templates/story/story.php?storyId=133779277>.



Section V: Public Policy

Insurance War: What is the Ultimate Cost?

Authors?

In the past few weeks, a lot of media attention has been paid to anti-abortion legislation, which is appearing at an alarmingly rapid pace in the United States. The issue of abortion has been heavily discussed in heated debates on the social, political, and religious scenes and together, these debates imply that no agreement will ever be reached. The legislation that has arisen and has been voted on recently, the No Taxpayer Funding for Abortion Act (H.R. 3) and the Protect Life Act, which notably suggest cutting the Title X Family Planning Program are not only shocking, but set a dangerous precedent for American women and healthcare in the United States.

Essentially, Republican representatives and governors throughout the country are using the current political climate, which began to show more conservative leanings after the 2010 midterm elections, to bring new legislation to the table, but not the legislation promised to help increase the number of available jobs or improve the economic deficit. Instead, they are proposing legislation that seriously endangers the possibility for women to make informed healthcare decisions for themselves.

On February 18, 2011, the U.S. House of Representatives voted to defund the \$317 million Title X Family Planning Program (Beyerstein). Planned Parenthood, the nation's leading private healthcare organization that serves over 3 million Americans, is one of the major recipients of funning from Title X. Planned Parenthood is well-known and trusted by women looking for care in uncomfortable situations as evidenced by studies showing that 1 in 5 women have visited one of the 800 Planned Parenthood healthcare centers in their lifetime (Richards). Although general free

clinics would not be affected by this legislation, the idea of walking into a free clinic in the middle on New York City, a clinic that does not have a reputation like that of Planned Parenthood might discourage women from getting the tests or help that they need. The loss of funding for such a recognized institution, which provides annual clinical screening for breast and cervical cancer as well as for STDs such as HIV for more than 1 million women, might discourage them from seeking out more expensive forms of testing in general (Planned Parenthood).

There are clear political agendas on the table and the economic arguments supposedly driving this legislation in the first place are being heavily questioned. However, there are additional, if not more pressing, bioethical issues to consider in the matter. All four of the guiding bioethical principles--autonomy, non-maleficence, beneficence, and justice--are violated by this legislation. The passing of this legislation, which takes away the funding of life-saving clinical treatments and screenings at Planned Parenthood, also threatens the autonomy of anyone who uses Planned Parenthood's health centers as their primary healthcare source or as a source of reliable information to guide decisions concerning healthcare (Davis). Any of the 1.4 million women who are on Medicaid and use Planned Parenthood as their main healthcare facility would lose their primary source of preventative healthcare under this legislation (Davis). Medicaid patients, in particular, would be cut off from Planned Parenthood's list of approved insurance providers. Not only would women without private insurance who rely on Planned Parenthood for all of their healthcare needs be affected, under H.R. 3, Americans with a private health care policy that covers abortion will see an increase in

taxes, making it less accessible for people to rely on coverage for abortion- related costs (Katz).

The legislation does not just affect the performance of abortion, but also bans Planned Parenthood clinics from receiving federal funding for birth control, cancer screenings, HIV testing, and other lifesaving care--in essence, removing its ability to provide beneficial preventative care (Planned Parenthood). This legislation affects all Americans, but disproportionately harms women of lower income. If access to basic healthcare is not available to all Americans, regardless of ability to pay, the principle of justice is neglected.



Courtesy of: Planned Parenthood Federation of America. (2011, February). *I stand with Planned Parenthood.*

Furthermore, the act of cutting off Title X violates the principle of non-maleficence. This decision will severely limit access for lower income Americans to testing for HIV and other Sexually Transmitted Diseases. Many women in communities where Planned Parenthood is a major source of healthcare will no longer have any clinic within their community which provides testing for sexually transmitted diseases including HIV and AIDS. Without the testing facilities women would be forced into a situation where they could be potentially and unknowingly be passing on these life-threatening diseases.

However, The Protect Life Act is perhaps the

most repugnant of all; if this bill is passed, health care providers will be unable to terminate a woman's pregnancy, even if her life is in jeopardy. Not only does this violate the Hippocratic Oath, the oath physicians must take to vow to help all patients, it violates the principle of non-maleficence because it advocates risking a mother's life by making a life-saving abortion illegal.

Before passing judgment on a free clinic, like Planned Parenthood, or legislation that may not seemingly affect women of upper socio-economic classes, one must remember that this legislation affects all women regardless of race, ethnicity, economic status or social standing. If any of these bills are passed, it is the start of a very slippery slope for the American healthcare system.

References

Beyerstein, Lindsay. (2011, February 23). Weekly Pulse: The Republicans' War On Women. Retrieved from http://www.themediaconsortium.org/2011/02/23/weekly-pulse-the-republicans-war-on-women/.

Davis, Sue. (2011, February 24). Defend Title X family planning funding. Retrieved from http://www.workers.org/2011/us/title x 0303/.

Katz, Alexandra. (2011, February 9). Stop antiabortion bill H.R. 3. Retrieved from http://www.columbiaspectator.com/2011/02/ 09/stop-antiabortion-bill-hr-3.

Planned Parenthood Federation of America. (2011, February 18). Statement by Cecile Richards, President of Planned Parenthood Federation of America, on Passage of Pence Bill to Eliminate Federal Funding for Planned Parenthood.

Planned Parenthood Federation of America. (2011, February). I stand with Planned Parenthood. Retrieved from https://secure.ppaction.org/site/SPageServer? pagename=pp ppol ws I Stand with PP.

Passport? Check. Visa? Check. HIV test... Huh?

Authors?

After 12 days at the American University in Cairo (AUC), my home university flew me back to the United States because of the increasing uncertainty surrounding the protests throughout the country. Security permitting, I plan to return to Egypt in the fall and have deferred my admission to AUC. Luckily, I won't have to resubmit an application. I will, however, have to get another HIV test. The Egyptian government requires recent HIV antibodies results from all foreigners wishing to obtain long-term work or student visas. My results will be negative again, and this policy won't affect me. But what would happen if my test were positive?

Mandatory HIV testing is a serious problem for those HIV-positive individuals wishing to live or travel abroad. As of 2008, over 70 countries require HIV testing for what they defined as long stays. Many of these countries were deporting foreigners with positive results and some banned HIV-positive visitors altogether (UNAIDS). These policies are not restricted to developing countries. The United States, in fact, refused the entry of HIV-positive travelers and immigrants from 1987 until January of last year solely because of their medical status.

While these restrictions only directly affect those individuals with HIV, it is important to consider this policy's ethical ramifications. Opponents of the policies, including the Joint United Nations Programme on HIV/AIDS (UNAIDS), argue that these restrictions violate basic human rights. They are absolutely right. Any policy that restricts travel, work, or residence based on an HIV test is discriminatory and demands redress. Following a meeting of the UN General Assembly in 2001, member governments signed the Declaration of Commitment on HIV/AIDS, thereby committing to enact appropriate legislation to eliminate all forms of

discrimination against people living with HIV (UN General Assembly). Almost 40% of the world's countries, however, still had HIV-dependent travel or immigration policies seven years after the resolution.



The continuation of these policies is not entirely due to bureaucratic inertia. These countries have lingering public health and economic concerns about HIV-positive foreigners [3]. HIV advocacy groups dismiss these apprehensions, but acknowledging them may be a more productive route. Even when groups like UNAIDS try to argue against reasons for keeping the restrictions, they tend to either neglect the specific situations within countries or suggest solutions that are wholly impractical. With a more careful evaluation of governments' reasons for enforcing HIV travel restrictions, we may be able to enact changes that alleviate these concerns, thereby invalidating arguments for the policies and leaving human rights as the main issue. Making concrete changes to the controversial situation may be, at the current time, easier than trying to win the ethical debate.

Although the World Health Organization concluded in 1988 that the screening of international travelers was an ineffective way to prevent the spread of HIV (World Health Organization), many countries still cite public

though, show that they may be. For example, a 2007 study found that 75% of Egyptian males in Lower Egypt felt condoms weren't necessary, and about 90% believed they were not at risk for sexually transmitted infections (Kabbash et. al, 2007). Thus, an HIV-positive person in Egypt may lead to more new cases than in America, where sexual education is better.

This, of course, raises the question of whether it is ethical to deny the rights of a small minority of people in order to protect the public. A traditional, human-rights-oriented answer would be no, but many countries have clearly prioritized 'the greater good' in terms of this public health concern. In order to change the grounds for this decision, more sexual education is needed to better inform individuals on practicing safe sex and on the reality of sexually transmitted diseases like HIV/AIDS. If the international community is truly interested in resolving the public health justification, they should help to change the situation in the country by funding and promoting this education.

In addition to the public health concern, many countries impose HIV-based travel restriction on long-term stays to prevent strains on their medical systems (Bisaillon, 2007). Even in the US, there are worries about the tax dollars that might be spent on HIV-positive visa holders (Dwyer, 2010). Countries are obligated to care for their citizens, so it's understandable that they may not want to allocate public funds to foreigners. However, opponents argue that a proper cost-benefit analysis must also account for the productivity associated with a visa applicant, in addition to his or her medical costs. UNAIDS also suggests that countries should evaluate each applicant's potential need for medical care during their stay. Such analyses would be nearly impossible to standardize and too cumbersome. A better solution, then, may be for the international community to fund more medical development projects and to supply HIV treatments, such as generic anti-retrovirals.

Effectively and practically addressing the justifications for HIV-based travel restrictions, rather than merely dismissing them as ethically wrong, may be the best way to eradicate these policies. Some may object to the methods we have suggested because of the reliance on international funds. We would argue that those who make such an argument support human rights only in theory, not practice--if one wants a country to change its legislation, one must give that country the tools to deal with the ramifications of that change. Empowering governments to protect the public health and economy, even with HIV positive foreigners, will make them receptive to these pressing human rights concerns.

References

UNAIDS. (4 March 2008). HIV Related Travel Restrictions. Retrieved from http://www.unaids.org/en/Resources/PressCentre/Featurestories/2008/March/20080304HIVrelatedtravelrestrictions

United Nations General Assembly (G.A.). (2001). Res. S-26/2, U.N. Doc. A/RES/S-26/2.

UNAIDS and IOM (June 2004). UNAIDS/IOM Statement on HIV/AIDS-Related Travel Restrictions. Retrieved from http://www.iom.int/jahia/webdav/site/myjahiasite/shared/shared/mainsite/activities/health/UNAIDS IOM statement travel restrictions.pdf.

World Health Organization. (1988). Statement on screening of international travelers for infection with HIV. WHO/GPA/INF/88.3

Kabbash IA, El-Sayed NM, Al-Naway AN, Shady IK, Abou Zeid MS. (2007). Condom use among males (15-49 years) in Lower Egypt: knowledge, attitudes and patters of use. East Mediterr Health J, 13, 1405-16.

Bisaillon LM.(2010). Human rights consequences of mandatory HIV screening policy of newcomers to Canada. Health and Human Rights in Practice, 12, 119-134

Dwyer, Devin. (5 January 2010). U.S. Ban on HIV-Postive Visitors, Immigrants Expires. ABC News. Retrieved from http://abcnews.go.com/Politics/united-states-ends-22-year-hiv-travel-ban

Alternative Medicine Should Follow Conventional Regulations

Authors?

demonstrated that the ability to induce adult fibroblasts into pluripotent stem cell status comes with a host of side effects. These harms associated

The term 'alternative medicine' often conjures up thoughts of witch doctors, remedies from old wives' tales, and horror stories of treatments gone horribly wrong. However, the landscape of American alternative medicine is drastically changing. The Journal of the American Medical Association reported that in the 1990's alone, the number of visits to alternative medicine practitioners increased nearly 50%, overtaking the total number of visits to American primary care physicians (Eisenberg et. al., 1998). While many experts believe Complementary and Alternative Medicine (CAM) is unscientific and should be prohibited, there is a substantial body of evidence showing that there may be more to herbal remedies than just ancient tradition, and that even if homeopathy is merely channeling the power of positive energy, CAM can improve patient well-being. By harmonizing and regulating the way CAM and Conventional and Orthodox Medicine (COM) are practiced, it is possible to minimize the risks patients bear while still allowing them to take full advantage of what both conventional and alternative therapies have to offer.

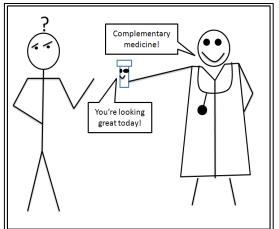
Herbal remedies, often marketed as dietary supplements, include a wide array of products, ranging from basic vitamin pills to more uncommon supplements originating from Traditional Chinese Medicinal (TCM) practices. No matter what the type, herbal remedies have become ubiquitous among average American consumers. Presently, nearly all grocery stores have an aisle stocked full of a veritable rainbow of supplements. However, despite all their popularity, dietary supplements remain one of the least regulated alternative medicines, in addition to being one of the most potentially harmful. Under current FDA guidelines, any product that is marketed as a 'dietary supplement' is in fact subject

to less regulation than food or even homeopathic remedies (FDA). There is generally no premarket approval required for a new dietary supplement, and one of the only requirements for manufacturing is, in the FDA's own words, that the manufacturers ensure that 'product label information is truthful, and not misleading.' While this requirement is great in theory, in practice it is often ignored.

For example, there have been many reported cases where mislabeling of alternative remedies has lead to dangerous results. Just last year a Chinese remedy touted to be a 'blood purifier' was taken off shelves in London after it was found to contain levels of arsenic that were nearly 30 times the acceptable dosage (NutraIngredients.com). Obviously these types of herbal supplements are neither safe nor effective. However, studies have been conducted on the effects of properly administered TCM remedies in comparison to the effects of placebo, and, although most comparative studies agree that there are significant biases in trials that show herbal remedies having a more positive effect than placebos, the many reliable trials reveal a neutral outcome. In specific case studies that compare placebo and herbal remedies, many TCM remedies have in fact shown to be more effective in managing certain disorders (Gao. 1999). It is clear that, if properly regulated and administered, herbal medicines could potentially provide health benefits to those who are interested. If not, they could at least provide some sort of positive placebo effect, which can be a powerful healing tool in itself.

While herbal remedies at least have active ingredients, those involved in homeopathic remedies are diluted until they are essentially water. Despite this, \$870 million was spent on homeo-

pathic remedies in the US in this past year alone (Deardorff, 2011). Unlike herbal remedies, there is no scientific basis supporting the benefits such treatments claim to confer. However, there is some evidence that the psychological placebo effect of homeopathy can improve patients' outcomes. Is it ethical to sell a glorified placebo pill with no underlying evidence of its efficacy? This question requires us to consider whether they might actually worsen patient health. The two major risks alternative medicines carry are: (1) unsafe production leading to toxicity and (2) patients substituting homeopathy for a standard treatment proven to be effective. In regards to the first risk, homeopathy is regulated similarly to "regular" drugs by the FDA in the US, but with some exceptions. The more serious problem is that patients of homeopathic practitioners often neglect more reliable medications, and are sometimes even warned against getting immunizations and other life-saving treatments. A recent example is the case of Gloria Thomas, who died of eczema, an easily treatable condition by conventional medical standards, when her parents ignored the advice of doctors and tried to only use homeopathy to treat her (The Daily Telegraph).



Unlike many in the science community who decry Complementary and Alternative Medicine (CAM) as consisting solely of unproven traditions, there are very meaningful reasons to keep it around, and even encourage it, contingent upon certain precautions being taken to avoid the previously mentioned tragedies. If properly regulated and prescribed, homeopathic and herbal remedies will not harm patients any more than conventional medicine. At the very least, the positive thinking it induces as a placebo can stimulate real and measurable healing. Thus we propose several mechanisms to enable an Ethical Application of CAM, or "EACAM".

The first and critical step towards EACAM is the creation of a more robust licensing and registry for homeopathy and herbal medicine practitioners. To obtain these licenses, a prospective practitioner would need to prove his or her understanding of the necessity of consulting with board-certified doctors and the danger of neglecting prescribed treatments in lieu of alternative medicine. Additionally, the license would require that they keep track of possible conflicts their treatments might have in common OTC and prescription drugs. Finally, the license would ensure that they maintain open communication with a patient's Conventional and Orthodox Medicine (COM) caregiver in order to ensure the patient is being treated conventionally as well-this would help avoid cases such as Gloria Thomas'.

Second, conventional doctors must also adapt to the rising number of patients seeking CAM alternatives. It is at least partially the responsibility of their doctors to enable them to safely do so. By explaining the possible benefits and risks, doctors can educate their patients and help them make an informed choice. Furthermore, they can point them towards licensed practitioners, promoting a safe fusion of medical treatments. Moreover, it would be just as unethical to deny patients these possible benefits as it would be to prevent them from taking medicine. Studies have shown that the positive thinking these treatments induce can have very beneficial effects on patients with diseases that may be lacking in

conventional treatments.

Finally, herbal remedies need to be regulated much more strictly by the FDA. Doing so would prevent instances where they contain harmful toxins, and would also allow for a clearer understanding of each remedy's composition. Similar to the use of homeopathic remedies, such regulation would prevent cases where alternative treatments interfere with the function of other drugs a patient is prescribed (which has been documented in patients taking HIV medication and certain herbal supplements).

By revamping complementary and alternative medicine to function alongside conventional and orthodox medicine, it is possible to achieve a unified medical practice that offers patients the best of both worlds. The American population has been pursuing the merits of alternative medicine for quite some time now, and it is high time that the FDA steps up, partners with conventional medical institutions, and follows suit.

References

Eisenberg, David M. et al. "Trends in Alternative Medicine Use in the United States, 1990-1997: JAMA 1998; 280(18):1569-1575

Dietary Supplements, FDA (2010) http://www.fda.gov/food/dietarysupplements/default.htm

"Breaking News on Supplements & Nutrition - EuropeUS Edition." NutraIngredients.com. Web. 27 Feb. 2012. http://www.nutraingredients.com/Regulation/MHRA

-finds-contaminated-Chinese-Ayurvedic-medicines>.

Gao, S. "A comparative study on the treatment of migraine headache with combined distant and local acupuncture points versus conventional drug therapy." Academy of Chinese Medicine. 1999

Homeopathy prospers, even as controversy rages. Julie Deardorff, LA Times (2011)

Homeopath Thomas Sam guilty of daughter Gloria's death. The Daily Telegraph (2009).



Beyond Beneficence – Physicians, Medical Education, and Intimate Partner Violence

Chloe Slocum

Over the past several decades, growing awareness of underreported forms of violence and the public health implications of endemic interpersonal violence have yielded a plethora of descriptive terms for violent behavior within intimate relationships. The words "domestic" or "intimate" distinguish these forms of violence (domestic abuse, domestic violence, intimate partner violence) from more public, and therefore more visible forms of violent behavior. Intimate partner violence (IPV)has also been referred to as gender-based violence, since 85-90% of cases of IPV occurring in the United States and upwards of 90% of cases in studies of developing countries document violence against women perpetrated by male partners. The cumulative prevalence of IPV among women presenting for emergency medical care is most frequently estimated as 22-35% with physicians detecting 5% of cases, although prevalence of patients' exposure to IPV in some studies has been upwards of 50%.^{2,3} Despite a growing awareness among health care professionals, organized preventative efforts to serve patients affected by IPV and training strategies to prepare physicians in identifying IPV in clinical situations remain lacking.3-

Although inroads in training physicians to identify and address IPV have been made by including relevant information in dominant texts of primary care, emergency medicine, and obstetrics-gynecology, standardized instruction and content relating to IPV are still not required components of undergraduate medical education. Occumented training protocols and efforts to educate physicians about IPV through textual materials in other specialties are even more scarce, despite the fact that medical professionals can encounter patients affected by IPV in all practice settings. The majority of in-

service training programs for medical professionals provide between 1-3 hours of instruction that attempt to raise clinicians' awareness of IPV and improve providers' identification of potential victims, interviewing skills, and counseling abilities when victims are identified.⁶ Such training is insufficient if the goal of training is to provide medical professionals with an overview of the behavioral issues involved in IPV, community resources, and a venue in which to examine their own attitudes and beliefs about IPV. Physicians may be learning the questions to ask that will identify potential victims, yet as one quote from a multisite study compiling testimony from health care professionals and community activists aptly states, "Physicians will not ask questions if they do not know how to deal with the answers."5

Various legal statutes concerning mandatory reporting of IPV have polarized physicians and legal scholars since healthcare professionals recognized that IPV is not a private matter contained within the "separate sphere" of a household. Rather, IPV is now seen as a reality of "epidemic proportions" that pervasively affects patients' medical and psychiatric wellbeing. 4,9 Mandatory reporting exists for certain crimes involving weapons or criminal acts, but even reporting of these crimes in cases of IPV have been argued by some to risk patient safety, discourage victims from seeking further medical care, and compromise patients' autonomy and confidentiality by taking away the victim's decision to involve the legal system ¹⁰ While all states in the U.S. mandate reporting by physicians of suspected child abuse and neglect, reporting in cases of suspected IPV is not universally mandatory and differs notably because it "violates ethical standards of confidentiality owed to the adult patient."9

despite much vocal debate about physicians' legal obligations towards IPV victims, providers and medical educators must realize that decisions to invoke legal processes are just one dimension of the patient-provider relationship and there exist steps to improve care for victims of IPV that do not breach physicians' duty to uphold patient confidentiality. These interventions, including more robust protocols for identifying victims and survivors and assessing their risk across specialties and improved training throughout medical education, are ineffectually implemented on a broad scale and are poorly studied. 5, 9, 11

Beneficence and nonmaleficence are the two most commonly cited ethical principles applied in caring for patients who may be victims or survivors of IPV. Beneficence guides physicians to diagnose and treat the "psychological, social, and even spiritual" harms that result from IPV as well as physical injuries. 12 Nonmaleficence directs physicians to diagnose cases of IPV in order to prevent additional harms to patients, for example, by unknowingly prescribing sedatives to patients who may be at heightened risk for suicide or substance abuse and possibly enhancing their sense of entrapment. 9,12 The principle of justice has less often been cited as a guiding principle in care for victims of IPV, but it is no less important in ensuring that patients who suffer harm as a result of IPV are given the best clinical care possible. The difficulty in focusing on beneficence and nonmaleficence, as has traditionally been the case, is that such an emphasis does not highlight the need for required protocols and enhanced training for medical professionals. By ignoring the importance of justice as a guiding principle, which has perhaps occurred as a backlash to laws that threaten to encroach upon patientphysician relationships, medical professionals risk relying on personal largesse rather than clinical reasoning to provide care for patients who are the victims or survivors of IPV when they are identified.

Required training for medical professionals that comprehensively addresses the needs of patients who are either victims or survivors of IPV must encompass the clinical skills needed to encourage patient disclosure, ensure patient privacy, confidentiality, and safety, assess patients' risk and access to medical and community resources, and evaluate medical professionals' own cognitive biases and misconceptions surrounding IPV. Mandating such training and implementing standardized protocols for identifying and serving the needs of patients affected by IPV would help counteract underreporting of IPV and enhance physicians' ability to provide optimal care for these patients. Since a history of IPV weighs just as much as, if not more, heavily than alcohol intake, occupation, or functional mobility on a medical health, it should thus be routinely queried as a review of systems in patients' medical histories. This would increase diagnosis and in turn make physicians better clinicians. Physicians and medical students who are competent at identifying cases of IPV and adept at assessing patients' risk, providing counsel, and mobilizing healthcare and community resources in the service of these patients would have a broadreaching and positive impact on the well-being of individual survivors as well as aiding in preventive, public health interventions. 13

Requiring rigorous training of medical professionals in the diagnosis and treatment of patients whose lives have been affected by IPV is problematic in several ways. The experience of questioning and listening to survivors of IPV may challenge students' and professionals' belief structures, fundamental trigger complicated defenses that may lead to professional distancing and emotional abandonment of patients, or threaten emotional decompensation in students or professionals who may have personal experience with IPV. Comprehensive curriculum reform that incorporates a greater focus upon identifying and caring for patients who have experienced IPV

must address practitioners' own attitudes and experiences with IPV and would do well to include training that aims to strengthen physicians' self-care. A recent study of first-year medical students revealed that 30-36% of trainees had personally experienced violence within a relationship as adults. Sufficient training for these medical professionals would undoubtedly demand resources, time, and the demonstration of clinical skills which are all too uncommon in contemporary medical training. And the demonstration of clinical skills which are all too uncommon in contemporary medical professionals would by nature be imperfect, since information on the prevalence and success of different training methods is still growing.

Nevertheless. controversy surrounding physicians' legal obligations to patients who have experienced IPV and a lack of resources should not deter the profession from recognizing the role of justice and the need for a new understanding of beneficence. In order for clinicians to recognize and best treat the physical injuries and mental distress of patients who have experienced IPV, they must be equipped with a robust armamentarium of clinical skills and emotional as well as medical understanding. Providing the best care for victims and survivors of IPV does demand that physicians address the potential for IPV. Incorporating comprehensive, standardized approaches towards IPV into medical professionals' education and clinical care will help students and physicians grapple with challenging clinical scenarios that may cross medical disciplines and cultural contexts. Just as physicians continuously augment their training by performing and practicing physical exam skills, reviewing current literature, and refining interviewing techniques, they must strive to recognize and offer the best possible care to patients whose lives have been affected by IPV and these skills should be rigorously assessed.

References

¹ Alpert EJ, Cohen S, Sege RD. Family violence: an

- overview. Acad Med. 1997 Jan;72(1 Suppl):S3-6.

 Abbott J, Johnson R, Koziol-McLain J, Lowenstein SR. Domestic violence against women. Incidence
- and prevalence in an emergency department population. JAMA. 1995 Jun 14;273(22):1763-7.
- ³ Hendricks-Matthews MK. Ensuring students' wellbeing as they learn to support victims of violence. Acad Med. 1997 Jan;72(1):46-7.
- Fischbach RL, Herbert B. Domestic violence and mental health: correlates and conundrums within and across cultures. Soc Sci Med. 1997 Oct;45 (8):1161-76.
- Ohen S, De Vos E, Newberger E. Barriers to physician identification and treatment of family violence: lessons from five communities. Acad Med. 1997 Jan;72(1 Suppl):S19-25.
- ⁶ García-Moreno C. Dilemmas and opportunities for an appropriate health-service response to violence against women. Lancet. 2002 Apr 27;359(9316):1509-14.
- Baker NJ. Strategic footholds for medical education about domestic violence. Acad Med. 1995 Nov;70(11):982-8.
- ⁸ Congdon TW. A medical student's perspective on education about domestic violence. Acad Med. 1997 Jan;72(1 Suppl):S7-9.
- ⁹ Jecker NS. Privacy beliefs and the violent family. Extending the ethical argument for physician intervention. JAMA. 1993 Feb 10;269(6):776-80.
- Hyman A, Schillinger D, Lo B. Laws mandating reporting of domestic violence. Do they promote patient well-being? JAMA. 1995 Jun 14;273 (22):1781-7.
- Alpert EJ, Sege RD, Bradshaw YS. Interpersonal violence and the education of physicians. Acad Med. 1997 Jan;72(1 Suppl):S41-50.
- Clark MD. Physicians and domestic violence. Ethical considerations. Council on Ethical and Judicial Affairs, American Medical Association. JAMA. 1992 Jun 17;267(23):3190-3.
- Rosenberg ML, Fenley MA, Johnson D, Short L. Bridging prevention and practice: public health and family violence. Acad Med. 1997 Jan;72(1 Suppl):S13-8.
- Cullinane PM, Alpert EJ, Freund KM. First-year medical students' knowledge of, attitudes toward, and personal histories of family violence. Acad Med. 1997 Jan;72(1):48-50.
- Alpert EJ. Making a place for teaching about family violence in medical school. Acad Med. 1995 Nov;70(11):974-8.

New York City's New Organ Preservation Unit

Authors??

As part of a new policy initiated last December. 911 calls for cardiac arrest in Manhattan will have two ambulances dispatched. The first will provide life-saving resuscitation while the other, the newly created Organ Preservation Unit (OPU), will preserve the deceased's organs for eventual transplant if resuscitation efforts fail. This new unit is currently undergoing a six month trial period and will attempt to verify eligibility and donor status, obtain family consent, and begin organ preservation techniques within the 20 minute window after death when the deceased organ's are still viable. The introduction of this unit, the first of its kind in the United States, aims to fill a growing need for organ transplants.

Over 6,500 people die each year waiting for an organ to be donated, and according to the New York Organ Donor Network, New York City alone had nearly 8,000 residents waiting for a transplant in 2009. Of the roughly 50,000 people who died in New York City area that year, roughly 600 qualified as organ donors, and of these, only 261 actually became donors [2]. These low numbers are partly due to the difficulty of becoming an organ donor. Roughly 95% of deaths in the area occur out of hospital, and current organ donation programs are limited to in-hospital deaths. By enabling individuals who die outside of the hospital to fulfill their wishes of having their organs donated, NYC administrators estimate that over 400 additional donors each year may be able to save lives by donating their organs.

The program was made possible with a \$1.5 million grant from the U. S. Department of Health Resources and Services Administration (HRSA) and is a partnership between Bellevue Hospital and the city's Fire and Police Departments. The Organ Preservation Unit will

be crewed by two trained EMT Organ Preservation Specialists, a Bellevue emergency physician, and a Family Services Specialist from the New York Organ Donation Network. To ensure that no life-saving effort is withheld, the OPU will remain out of sight and only enter after the patient is pronounced dead; at no point will the primary EMTs know of the patient's donor status or of the OPU's presence. After a police detective verifies that a criminal investigation is unnecessary, the OPU will have roughly 20 minutes to determine if the patient is an eligible donor (age 18-59, died of cardiac arrest, disease free, and has an organ donor card), obtain consent from the family, and begin transport to Bellevue. Currently, only kidneys are targeted for donation and Bellevue is the sole receiving hospital.

Along with the visceral reaction to its "creepy" implications, there have been several ethical issues raised by critics of the program. Some fear that the existence of the OPU will undermine public trust in emergency care, and others question the allocation of EMT resources to deceased persons instead of other possible emergencies. Many critics are concerned that family members will not approve of the unit's treatment of the deceased, even if he or she were registered organ donors, and that 20 minutes is not sufficient for family members in shock to process the situation. Finally, some are concerned that the removal of the body may impede criminal investigations.

In order to address these issues, the program has been purposefully designed to be conservative. The Organ Preservation Unit's presence will not be made known to the EMTs performing resuscitation until after death is declared to ensure that full effort is made to save the patient. A police detective will clear the scene of investigation, and blood samples will be taken to

test for poisoning. Transport by the OPU requires the deceased to be an organ donor and for family present to provide consent. A Family Services Specialist will assist the family in making an appropriate decision, and transport will not happen if the family has any qualms. The question of whether twenty minutes is sufficient to make this decision is arguable and remains to be seen from the trial period of this program.

Every organ donor can save as many as eight people and improve the lives of many more. Though only in its pilot phase, the Organ Preservation Unit has tremendous potential for saving lives. The program's officials stated that even if no organs are transplanted, the pilot would provide useful information regarding the protocol, since much of the program relies on a delicate balance between treatment and consent. There may still be controversies and ethical debates surrounding the Organ Preservation Unit, but it is clear that if implemented correctly, this unit may save thousands of people in the NYC area while not infringing on individual liberties and the quality of emergency care.

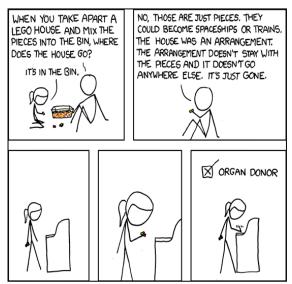
References

HHC Press Release. (Dec. 1, 2010). "Mayor Bloomberg And New York Organ Donor Network Launch Innovative Organ Preservation Program." In New York City Mayor's Office. Retrieved March 8, 2011, from http://www.nyc.gov/html/hhc/html/pressroom/pr-20101201-ny-organ-donor-network.shtml.

Hartocollis, Anemona. (Aug. 1, 2010). "A Plan to Recover More Organs for Transplant Runs Into Difficulty." In the New York Times. Retrieved March 8, 2011, from http://www.nytimes.com/2010/08/02/nyregion/02organ.html

Hartocollis, Anemona. (Dec. 1, 2010). "City to Deploy Ambulances to Save Organs." In the New York Times. Retrieved March 8, 2011, from http://www.nytimes.com/2010/12/01/nyregion/01organ.html

JEMS Web Team. (Dec. 1, 2010). "NYC, FDNY Organ Recovery Program." In JEMS. Retrieved March 8, 2011, from http://connect.jems.com/forum/topics/nyc-fdny-organ-recovery



Source: http://xkcd.com/659/

Obesity in America

Lee Hingula

Obesity is one of the most costly diseases in the United States With over one third of the US population obese and another third overweight, Americans are becoming afflicted by the various sequelae of obesity at an alarming rate (CDC 2011). Estimates of the direct cost of obesity are approximately \$147 billion annually, with major obesity-related diseases like diabetes costing about \$92 billion annually (Reinberg 2010). As part of a solution to the obesity epidemic, a public health campaign against obesity must address several ethical issues. The patient's autonomy to choose food and be in control of their health must be balanced against the justice of paying for the treatment of this epidemic. Since risk is pooled, either in private insurance or in governmental insurance plans, one issue to consider is that the thin will be paying for the healthcare costs of the obese. From the perspective of a physician, the duties of beneficence and non-maleficence require that we treat obesity. The question arises of how best to treat this disease. Should we focus on tertiary prevention, treating heart disease and obesityrelated malignancies? This involves costly interventions such as revascularization procedures, but such procedures are relatively infrequent. Should we focus on secondary preventive measures such as providing glucometers for diabetics and medications to decrease cholesterol? These measures are very frequently utilized in our healthcare system but are less costly than expensive procedures. Is there a primary prevention role that occurs before a patient even sees a doctor? This might manifest in agricultural policy changes or higher taxes on less healthy foods. The principle of justice requires that we take the time to best allocate resources to improve health in a way that reduces costs to society.

Focusing on tertiary prevention measures may

seem counterintuitive, but it has its uses. It is estimated that the United States spends \$100 million on cardiac catheterization annually. While this may seem to be a large amount of money, the efficacy of the procedure is well-documented and dramatically improves quality of life. It may seem at first to make more sense to treat diabetes and hypertension before they occur, but 118 patients with hypertension are the equivalent to treating one stroke patient (Hyman and Pavlik 2000).

Thus, we are spending an inordinate amount of money on preventive medicine to prevent complications for a very small number of people. Cost effectiveness aside, focusing obesity treatment efforts on the most dangerous conditions violates beneficence and non-maleficence. It is far less psychologically damaging to take a pill every day than to be rushed to the hospital while having a heart attack. Tertiary prevention measures also seem to violate the principle of justice that funds need to be allocated such that the greatest number of people receives the greatest benefit.

Secondary prevention not only involves preventing disease and disability once obesity has occurred, but also attempting to reverse obesity. Unfortunately, this has been a costly and largely ineffective endeavor. The weight reduction industry costs the United States approximately \$61 billion a year (Adams 2005). Given that obesity is increasing, this is money spent in a largely ineffective way. However, some interventions are proven to be effective. For example, certain weight reduction medications and surgeries are effective. Sibutramine and orlistat are currently licensed for the treatment of obesity and are effective not only in reducing weight, but also of improving conditions like diabetes associated with obesity (Hollander et al. 1998). Bariatric surgery is also

very effective, but may lead to revisions, plastic surgery and malabsorption of fat soluble vitamins. If a patient cannot reduce weight on his own, is bariatric surgery or use of medications with side effects warranted? Is this beneficial in that the condition is being treated, or do the side effects and possible adverse outcomes outweigh the fact that obesity is almost completely preventable and reversible merely Although counseling, gym with diet? memberships and physician encouragement may result in improved weight control in some individuals, the cost of these interventions would be great and insufficiently effective to warrant their widespread use. Secondary preventions are the middle road, a bandage on the problem, and do not result in fewer obesity-related complications for the price paid in this country.



Source: obesityinamerica.org

There are also primary measures of disease control, the perhaps idealistic view that obesity can be prevented. The issue is not solely an act of willpower because the economics of obesity starts in the grocery store. Salsa, chips, peanut butter, beef and cookies are alike in that they are made with corn products. Since we subsidize corn in this country with a minimum price of

\$1.90 per bushel under the Farm Bill of 2007, farmers have no incentive to grow anything else (Riedl 2007). As a country we are inventing uses of corn. It has made its way from food to fuel in the form of ethanol. The economy is creating large scale work-arounds to deal with a large influx of corn into the market that cannot be sold. The "fat tax" that was touted in New York, although a clever idea to prevent the consumption of fatty foods, is just another workaround. Why can we not subsidize other crops instead? Could green leafy vegetables be the cheapest item to buy in a grocery store if we subsidized them instead? It is certainly not for the ease of growing corn that it has been selected. To the contrary, it requires enormous amounts of water and depletes the soil such that large scale crop rotation is necessary for several years after a field grew corn. Focusing on agricultural reform satisfies our duties to beneficence and non-maleficence to our patients. It is a form of economic justice in utilizing the least amount of money to enable the best health for Americans. It does not perhaps respect patient autonomy, though. It may force certain people, especially poorer segments of the population, to eat healthier when they might prefer not to do so. However, Obesity is a disease of great racial disparity, and the benefit from preventing obesity far outweighs the issues of dictating people's diets. Unlike the ban on trans-fats in New York, agricultural reform does not tell people what they can and cannot eat, but rather it provides economic incentives to make healthier choices. The major ethical issue with obesity is that it is a disease that can be effectively prevented and the United States is not preventing it.

This is only one of the major public health issues in this country, but other issues do not need to supersede funding that could be used for other purposes. It is money that could be used for the primary, secondary and tertiary of conditions that are currently underfunded. It is money that could be used for research. Although these may

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seem to be largely an issue of economics, fair use of funding is an ethical issue. Solving the agricultural root of obesity is the most just use of the funds that are currently spent on this problem. Although this may not respect patient autonomy perfectly, the choice of what to east is far less ethically problematic than the choice of which form of heart surgery to undergo. Thus it would be less ethical to approach the problem from the other approaches discussed here.

References

Adams, Mike. "U.S. Weight Loss Market Worth \$46.3 Billion in 2004 — Forecast to Reach \$61 Billion by 2008." 2005. http://www.naturalnews.com/006133. html. Accessed January 25, 2011.

Center for Disease Control. "Overweight and Obesity." 2011. http://www.cdc.gov/obesity/index.html. Accessed January 25, 2011.

Hollander P.A., S. C. Elbein, I. B. Hirsch, D. Kelley, J. McGill, T. Taylor, S. R. Weiss, S. E. Crockett, R. A. Kaplan, J. Comstock, C. P. Lucas, P. A. Lodewick, W. Canovatchel, J. Chung, and J. Hauptman. "Role of orlistat in the treatment of obese patients with type 2 diabetes. A 1-year randomized double-blind study." Diabetes Care. 1998. 21(8):1288-94.

Hyman DJ, Pavlik VN. "Self-reported hypertension treatment practices among primary care physicians: Blood pressure thresholds, drug choices, and the role of guidelines and evidence-based medicine." Arch Intern Med. 2000. 160:2281-2286.

Riedl, Brian M. "How farm subsidies harm taxpayers, consumers and farmers too." 2007. http://www.heritage.org/research/reports/2007/06/how-farm-subsidies-harm-taxpayers-consumers-and-farmers-too. Accessed January 25, 2011.

Reinberg, Steven. "Almost 10 percent of U. S. medical costs tied to obesity." Daily Health News. 2011. http://abcnews.go.com/Health/Healthday/story? id=8184975&page=3. Accessed January 25, 2011.

"Your Genes? Your Health? Your Data?"

Author? and Missing References

This week, members of the FDA advisory panel will come together to discuss government regulation of direct to consumer (DTC) genetic testing. A relatively new product to appear on the ever-expanding radar screen of commercial biotechnology, DTC genetic testing offers customers the chance to have their DNA sequenced and analyzed without any involvement from medical infrastructure. The idea is that genetic scanning will reveal predispositions to late-onset diseases and will allow patients to take potentially life-saving preventive measures while avoiding the consequences of having results of their testing appearing on their permanent medical record. Those who argue in favor of DTC testing appeal to the principle of customer autonomy, claiming it is their right to have access to their genetic information. However, there is an something paradoxical implied within this line of reasoning: the more we learn about individual genetic make -ups, the more conclusions we will be able to draw about wider genetic communities, resulting in a less individualized view of this information . Eventually, this paradox will force us to dramatically reconsider the principle of individual autonomy itself.

The idea of customer autonomy plays heavily in the marketing rhetoric of DTC testing services. Even a cursory scan of some of the top companies' websites reveals a strong emphasis placed on the agency and individuality of their customers. Take for example, 23andMe's slogan, "genetics just got personal," or Navigenics' commitment "to empower you with genetic insights to help motivate you to improve your health, keeping you in control of your genetic information." The logic is quite clear: as DecodeMe puts it, it's "your genes, your health, your data."

Yet despite all the emphasis placed on the

personalization and individuality of the service being offered by DTC companies, it is worth remembering that most, if not all of them, retain the right to hold onto customer's genetic information for the purposes of their own research and development. Provided a guarantee that genomes are de-coupled from any personally identifying information, those who endorse this service are content to give the company free reign to conduct research with their depersonalized genetic information. This move towards treating genetic material as impersonal, objective information, however, marks the beginning of an important shift that will begin to challenge traditional conceptions of individuality and autonomy.

It is important to remember the fact that genetic material carries information not only about individuals themselves but also about their families and their wider communities. As we deepen our interpretation and understanding of the human genome, we increase the amount of meaningful information that can be gleaned from any given genetic analysis. The increased stock of human genetic data being analyzed by DTC testing will undoubtedly help to expedite this understanding, helping to pin point individual and group susceptibilities towards certain diseases. It is perfectly conceivable then, that in the future, the results of a supposedly individualized DTC test will contain crucial information concerning the health and wellbeing of both individuals who sent in their DNA for testing and their communities. This will open a new ethical playing field in which questions of confidentiality and consent— concepts firmly rooted in current individualistically oriented bioethical thinking—will be increasingly put to the test. Those providing genetic analyses will experience a growing responsibility to report back to the wider genetic community of an individual, whether their DNA was sequenced in

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confidence or not. In this way, a shift away from the present day framework of an individualistic bioethics towards a new more communitarianbased approach is something we can likely come to expect.

For the time being, blindly deferring to the autonomy of individual customers and endorsing DTC genetic testing raises numerous immediate ethical concerns. Some worry that the absence of a genetic counselor or other medically trained person to help customers interpret the data will lead people to draw false and likely emotionally trying conclusions. Others worry that this type of technology could erode physician-patient relationships and open up a space for the unauthorized practice of medicine. Critics have accused companies offering meaningful information to clients of false advertising, pointing out that current limitations in our ability to infer significant information from human genetic data in fact preclude the veracity of many of these claims. Still others see the current lack of possible interventions that can be made in response to most of the information provided as rendering the tests superfluous.

Hopefully, these valid and important concerns will guide the FDA in deciding what immediate regulations need to be put on DTC genetic testing. Whatever their ruling, in the long run, those of us skeptical of the extent to which the principle of individual autonomy can be productively employed in this arena may be pleasantly surprised with the resolution of bioethical issues arising from advances in genetic testing technologies.

References

Section VI: BioCEP 2011

The Right to Demand Proper Compensation: Theravada Buddhist and Capitalist Perspectives

Larry Geyman Missing References

Oftentimes, bioethical discussions tackle issues concerning the rights of the patients, including questions of autonomy and reasoning capacity. However, issues relating to the employees of the healthcare system, namely physicians and nurses are just as important. What are the rights of healthcare workers in terms of their ability to demand greater compensation and an easier working environment when faced with symptoms of professional burnout? Is it morally and ethically permissible for a healthcare worker to strike? Following a case study, this paper seeks to resolve these bioethical questions from both Theravada Buddhist and Capitalist perspectives.

First, we introduce a bioethical case, through which we will discuss the approaches of the two schools of thought. To summarize, nurses at a university hospital began to display symptoms of professional burnout. There was a grave shortage of nurses in the nation, while the aging population required all the more care and attention. After convening to discuss their situation, the hospital's 220 nurses agreed that their stress level had increased beyond a tolerable level. The low salaries and increasingly difficult work environment had led these nurses to demand a salary increase in line with the amount of work they were required to perform, as well as an increase in full-time positions within the busiest nursing units. Several nurses agreed: should the hospital disregard their requests, a strike was not out of the question.

The hospital required the nurses to give ten days notice before engaging in a strike, but this short period of time would not give the hospital enough to time transfer and give accommodations to the most ill patients. Additionally, the strike would expose the entire patient population to great inconveniences and medical risks. Additionally, in the past, hospitals confronted with nurses strikes have simply hired registered nurses to essentially cross the strike zone. These interim nurses make a considerable income during their employment. Should the hospital give into the demands of the striking nurses? Are health workers even permitted to strike, knowing full well that their course of action jeopardizes the health and safety of hundreds of patients?

Before we attempt to consider this bioethical dilemma from a Buddhist perspective, we offer a brief overview of Theravada Buddhism. The Theravada Buddhist tradition in Thailand has as its ultimate goal the attainment of Nirvana, or the cessation of suffering and the resolution of one's karma. Before this spiritual, physical and psychological death can be reached, one must first achieve Enlightenment, a state in which ones karmic footprint, so to speak, is made clear and one understands and envisions his path to Nirvana. The path to Enlightenment often consists of following the Four Noble Truths, laws set down by the Buddha centuries ago to assist his followers in ending the suffering of their existence.

As abstract as Theravada Buddhism may appear, one may deduce hundreds of practical laws and values that an adherent may follow in order to, if not attain Nirvana, at least lead a balanced life with a minimal karmic footprint. In short, we argue that Theravada Buddhism does not condone the decision to strike and should have many reasons to condemn it.

There are three main reasons for this conclusion. The first deals with the role of material goods in Buddhism. A Theravada Buddhist seeks to sever all ties with the material world, as he understands all material goods as inducing vices, such as avarice, desire, jealousy, etc. These emotions and states all prolong one's karma, contrary to the goal of Buddhism, and ultimately fuel the ego-desire, or the idea that there is an "I" that actually experiences the aforementioned sentiments.

The effects of focusing on material goods can hinder one from attaining a balanced life. Material goods ignite passions, leading to spiritual, psychological and even physical upheaval. Good passion and evil passion, avarice and healthy ambition all contribute to one's karma. Therefore, it is in the nurses' best interests to avoid a preoccupation with increased compensation, in order to minimize their karmic footprint and promote a more balanced, less volatile psychological state and life in general.

The second argument for our conclusion refers to an even more abstract idea: the negation of self. If we extrapolate the idea of rejection of materiality to an extreme, we come to realize that our bodies themselves are simply material shells surrounding our ego, our true inner self – what many religions refer to as a soul. Yet Buddhism takes this idea one step further and renounces the soul. We touched upon the rejection of egodesire and here we address it fully. Buddhism rejects the idea that there is a self - there is nothing, no consciousness, no "I". Indeed, the title used to address monks, means roughly the "movement of existence." Monks do not even acknowledge each other's existences – they only perceive karma and understand that one's existence is merely a collection of karma that could have collected into, for example, a leaf, a stone, or a raindrop.

One way to not concentrate on the self is to do the converse: concentrate on others. This is a

practical and relatively easy way for an individual who wishes to remain in the social framework to lead a more balanced life and reduce his karmic footprint. Now, of course, at their core, other individuals are merely material contrivances, as well; however, the key point here is that the nurses wish to remain in society and do not desire to attain Nirvana. As such, we must draw a line and certainly, in this situation, we must allow the nurses to acknowledge the existence of other bodies in order to successfully carry out their duties.

The third reason concerns a more practical tenet of Buddhism – Theravada Buddhism absolutely condemns the killing of other human beings. The act of killing another individual yields a powerful wave of karma that may take ages to fully exhaust. Even the act of placing another individual in harm's way will yield a level of karma corresponding to the nature and severity of the danger. Again, for a Buddhist, karma prolongs the suffering of existence and does not lead to a balanced and peaceful life. Thus, the nurses ought to refrain from risking the health of their patient and should not go on strike.

Moreover, there are karmic repercussions that may appear in this life or the next, which one certainly would not want to instigate. Not pertaining strictly to this point, but still interesting to note, is the fact that not one of the Buddhist reasons against striking concern the victim. Instead, all concern the perpetrator. The victim, by receiving an action, has not led to a prolongation of his karma. Thus, Buddhism would have relatively little to say about the condition if the victim, especially considering the individual will be re-born and given more opportunities to reach Nirvana.

As one can see, Theravada Buddhism would likely have several qualms with the nurses' decision to go on strike. Yet how would a strong believer in Capitalism, a more Western, and especially American, manner of reasoning,

respond to the nurses' call to action? Following a Classical ideology, the nurses are simply responding to market forces – there is a high demand for nurses and a low supply and thus, wages ought to increase. In this framework, the nurses have a right to demand proper compensation for their labor, time, and energy. Capitalist reasoning does not necessarily take into account the morality of an action per se – one can simply state that the nurses' actions are natural given human tendencies and methods of reasoning. The morality and value judgment come in the corollary idea that it is immoral to preclude the nurses from receiving proper compensation.

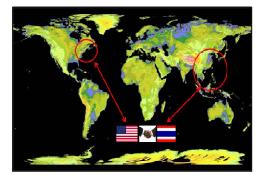
It is interesting that this point does take into the account the effects of the nurses' actions on the patients, which was absent in the karma-minded reasoning of Theravada Buddhism. One can certainly make a case that if the nurses do not strike, they will undoubtedly expose more patients to harm in the long-term future than in the short-term by going through with the strike. If the nurses continue to toil in such an exhaustive work environment, pushed to the brink of their nursing and personal capabilities, their ability to provide proper care will suffer. Thus, according to this utilitarian argument, more patients may end up being harmed in the future than in the near present. Therefore, nurses with the obligation to provide the best care, ought to alleviate their burnout through a strike if necessary.

In addition, if it is impossible to tell whether patients are harmed due to the strike itself or on account of continued improper compensation, where does one place the blame? The nurses are merely responding to market and societal pressures and are acting naturally and accordingly. In fact, in a capitalist framework, the culpability lies with the hospital administration for not increasing their wages. The Capitalist system, ideally, responds to such cases of misbalance between supply and demand by seeking a return to an equilibrium state. The

nurses, through a strike, are hoping to return to this equilibrium. It is the hospital administration that now has the power to grant or prevent a return to equilibrium.

How are these two competing philosophies resolved? Theravada Buddhism mandates that the nurses not concern themselves with compensation, yet Capitalism entails the exact opposite. Theravada Buddhism also states that one may reduce his or her attachment to the egodesire by focusing on the well-being of others. we can reconcile Buddhism and Capitalism by separating the intentions from the effects of the nurses' actions. If the nurses demand proper compensation because they believe this will reduce professional burnout and allow them to give more efficient care and attention to the patients, they will have few rifts with the mandates of Theravada Buddhism because the intention of their action concerns the spread of well-being and lacks a focus on the self. On the other hand, Capitalism is not wholly concerned with the intentions of actions – the effects are more important, namely, that market pressures are relieved and a return to equilibrium is established. A Capitalist would not distinguish between a selfish or selfless intention. Instead. all that would matter is whether or not the nurses strike.

Thus, Theravada Buddhism, an internal abstract philosophy, and Capitalism, an external, practical philosophy, can be reconciled specifically because they target two different components of an action. Buddhism concerns itself with the intention of an action; Capitalism, the effect. Thailand is a rapidly growing and industrializing nation and has experienced massive economic growth in the past fifteen years. Because Thailand is largely nation of Buddhists, it is all the more necessary to reconcile Theravada Buddhist philosophy with Capitalist thought in order to spur future economic growth, while keeping in line with national Theravada Buddhist ideology.



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