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Toward a Fairer Macroallocation of Biomedical Resources by Constraining Microallocation's Market-Driven Excesses

By

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> *Are you unaware that vast numbers of your fellow men suffer or perish from need of the things that you have to excess, and that you required the explicit and unanimous consent of the whole human race for you to appropriate from the common subsistence anything besides that required for your own?*
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> ■ Jean-Jacques Rousseau, 1755

The fundamental right to life, human dignity, and personal freedom requires food, safe water, shelter, a basic level of education, and at least a minimum acceptable standard of healthcare. As with other goods and services that are subject to resource constraints, preventive healthcare and clinical intervention are not available to hundreds of millions of people, most in developing countries in Africa, Asia, and South America. These regions represent the bulk of humanity and their medical needs are underserved, whereas in the United States, which represents a minority of humanity, market-driven allocations of resources have allowed the healthcare system and biomedical research to pursue, not just the basic needs of the many, but the vain desires of the few who have the ability to pay for what must be considered luxury treatments.

The moral question that needs to be addressed is to what extent should market forces be allowed to create an unfair distribution of benefits to the few when humanity at large holds a claim on biomedical knowledge and each person has a right to basic healthcare? Even those who can afford to pay for luxurious treatments, such as cosmetic alteration, genetic enhancements, and extraordinary life support measures, may not have an unbounded *positive right* to do so when scarce medical resources prevent their fellow citizens from experiencing the most basic preventive care, such as clean water, sanitation, minimal nutritional requirements, prenatal care, inoculations, and relief from easily treated medical ailments, such as pain, dehydration, diarrhoea, influenza, and the childhood diseases.

As a matter of social justice, public policymakers have an obligation to: (a) ensure basic healthcare opportunities to all, regardless of income, (b) provide for equitable distribution of the real costs and benefits of extraordinary treatments, and (c) ensure that if anyone is to be negatively affected by medical research and unequal distribution of medical care, at least a proportional share of the benefits will

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accrue to the most negatively affected groups. In a connected world of travel and commerce, where pandemics threaten all of humanity, its is morally wrong and short-sighted to address these issues in any other manner than via a global strategy.

The Plight of the Many

Even for basic medical care, the entire U.S. system seems to be in a crisis. According to Munson, “A crisis exists in a social institution when factors are present that tend to destroy it or render it ineffective in achieving its goals. Two major factors are present in the American health care system that put it in a state of crisis: the increasing cost to the society of health care (despite the advent of cost-control policies) and the failure to deliver at least a decent minimum of health care to everyone who needs it.”

The cost of health care takes more in gross domestic product (GDP) than education and defense combined, amounting to over $1 trillion annually or $3,800 per person. As a percentage of GDP, the cost of health care has tripled since 1960, going from 5.3 percent to 15 percent of GDP (Munson 805-806). Even with this significant level of funding, the health care system is failing to deliver an adequate minimum standard of care for all. The number of people without medical insurance exceeds 44 million, up from 29 million in 1979. Half of those without insurance are children or families with children, and children make up over 25 percent of the uninsured (Munson 807). Since people leave and enter the insurance rolls, often due to layoffs or job changes, estimates of upward of 60 million people are uninsured for at least some of the time during the year (Munson 807). When people find new employment, it is often with smaller companies that either do not offer health insurance, or limit coverage to the employee without covering the employee’s family, or limit the dollar amount of coverage or types of procedures. Munson cites studies that show that more than 10 percent of the population receive no care at all and that 4 million people who actually need care do without it. To exacerbate the situation, when the uninsured or underinsured delay seeking medical treatment, frequently the result is a disease that could have been treated effectively and inexpensively at an earlier stage (Munson 808-809).

More sophisticated treatments, such as transplantation of kidneys, livers, hearts, lungs, bone marrow, corneas, and skin, are common; however the need remains great. Munson quotes statistics based on 1996 U.S. data that showed,

> “While…more than 20,000 people received transplants at the nation’s 278 transplant centers, more than 3000 more people died waiting for organs. On the last day of 1996, 50,407 were on the transplant waiting list, and during the year, there were a total of 33,000 new registrations. For every organ transplanted, 2 more people enter the waiting list, and those on the waiting list currently die at a rate of 10 people a day” (Munson 737-238).

There is also the spectre of global pandemics. In the U.S., only about 20 percent of the roughly 1 million people who are HIV positive have insurance adequate to cover most of the expenses for $12,000 worth of drugs and $5,000 in laboratory tests and doctor visits (Munson 334). On a global scale, 1997 United Nations statistics estimated the spread of HIV to have reached over 306 million, two-thirds of whom lived in the countries of sub-Saharan Africa, who can not afford the expensive combinations of drugs and treatments available in the U.S. The U.N. estimates that 1,600 children a day are infected with HIV and 1,200 children die of AIDS daily (Munson 343). Recent reports from the United Nations indicate that in 2003 over 46 million people had AIDS, over 5 million were newly infected, and over 3 million died this year.[1]

Ismail Serageldin, the Director of the Library of Alexandria in Egypt, notes the stark differences between the haves and have-nots. The differences between the top 20 percent of the world’s population and the bottom 20 percent are even more extreme and the gulf seems to be getting wider over time.[2] The

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[1] Reported on *The News Hour with Jim Lehrer*, PBS, November 25, 2003.

[2] For example, the top 20 percent consumes 85 percent of the world’s income, while the bottom 20 percent lives on 1.3 percent of the world’s income. A generation ago, the top 20 percent were 30 times as rich as the bottom 20 percent. Today, they are more

richest 15 persons have more wealth than the combined GDP of all of sub-Saharan Africa's 550 million people (Serageldin 55-56). So, given the reliance of the medical establishment on market forces, it is no surprise that, not only is basic healthcare tenuous in the U.S., but it is almost non-existent for billions of fellow world citizens. According to Serageldin, over 1 billion people do not have access to clean water, 2 billion have no access to adequate sanitation, 1.3 billion people in cities breathe air below the standards set by the World Health Organization, and 40,000 persons die from hunger-related reasons daily.

When we consider exporting America's expensive pharmaceutical and medical wonders to the developing world, we have to recognize that 1.2 billion people live on less than $1 U.S. per day (Serageldin 55-56). Speaking of his work with the poor in Haiti, Paul Farmer notes that, "In a poor country tightly bound to the rich one, real infections continue to kill off the poor, and we are told sternly to look harder for cheaper, more cost-effective interventions" (Farmer xiii). According to Lawrence Hinman, " We do not deserve to be born into an affluent society any more than we deserve to be born into an impoverished society. However, we do benefit from the exploitation of poorer societies" (Hinman 16).

There is also suspicion that research funds are flowing to the diseases of the rich, where the highest profits may be garnered. "It is inconceivable that of the 1,233 drugs that have been approved in the last decade, only 11 were for treating tropical diseases [the region where most of humanity lives], and of these, half were intended for livestock, not humans," notes Serageldin. He goes on to observe that, "It is inconceivable that many of the persistent issues of child nutrition that could be tackled by changing the nutritional content of crops are receiving so little attention" (Serageldin 58). Likewise, Farmer reminds us that even limited use of antiretrovirals could have an immediate and substantial impact on South Africa's AIDS epidemic (Farmer xxvi).

Protecting Vulnerable Groups from Biomedical Abuses

This paper addresses the need for a more "qualified utilitarian" approach to biomedical research and treatment allocation that seeks to maximize the overall benefits to society while providing a fairer distribution of benefits and costs than is found in contemporary practice. Such an argument appeals to the logical sensibilities of those who must make tough decisions on allocation of scarce medical resources. However, though we seek objectivity, one should not be fooled into believing that such objectivity actually exists in practice. Human beings who come to the decision space with biases, presuppositions, prejudices, and human frailties make these decisions. The biomedical community, as well as the individual practitioner, must be vigilant in their efforts to recognize subjective bias and make adjustments for it. Modern technology, especially medical technology, has taught us that <u>if</u> anyone is to be negatively affected by an experiment, new procedure, or withholding of treatment, it will be the poor, the powerless, and those of color.[3]

Perhaps the most egregious of human experimentation, with the exception of the Nazis doctors of World War II, has come to be known as the Tuskegee Experiment. From 1932 to 1972, the U.S. Public Health Service conducted *The Tuskegee Study of Untreated Syphilis in the Negro Male* with 600 subjects

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than 70 times as rich. The richest three persons on earth have more wealth than the combined GDP of the 47 poorest countries (Serageldin 55-56).

[3] According to Munson, although there are many factors that contribute to the racial disparity in health statistics, including environmental, nutritional, stress, genetic, and income factors, it remains striking to note that African Americans constitute the highest death rate of any group in America. While the general rates of heart attacks, strokes, and cancer have declined, Blacks are still more likely to suffer them sooner than Whites. Black people enjoy eight fewer years of relatively good health than do Whites or Hispanics. Cancer has increased 62 percent among Black males, compared to their White counterparts. While the death rate among women due to breast cancer decreased by 10 percent between 1990-1995, the death rate among Black women remained steady and they are twice as likely to die from beast cancer as White women. Diabetes among Blacks increased by three times that of Whites. In addition, Native Americans have higher levels of diabetes. Hispanic Americans suffer from higher rates of stroke. Puerto Rican children are more prone to asthma. Tuberculosis among Asian Americans is 15 times higher than among whites (Munson 267-268).

treated with placebos without informed consent.[4] As a result, over the 40 years of the study, 28 men died, 399 diagnosed syphilis sufferers went without treatment, 201 underwent placebo treatments for syphilis that they did not have, the government paid out $10 million in out-of-court settlements, and finally in 1997 President Clinton formally apologized to the survivors. Clinton noted that, "What the United States did was shameful, and I am sorry" (Munson 255-257).

African Americans have had a long-held suspicion that the emergency wards of county hospitals treated them like experiments and teaching cases. The Tuskegee Study did more damage than any other single event to promote distrust of doctors among the Black community.[5] However, it was not the only abuse perpetrated upon the Black community. As late as 1973, two Black sisters from Montgomery, Alabama, a 12 and 14-year old were surgically sterilized without their parents' consent. An investigation revealed that in the same town, 11 young girls (10 of them Black) had also been sterilized. In Aiken, South Carolina during the early 1970s, 18 out of 18 Medicaid funded sterilizations were of Black women (Munson 293).

More proof of bias, insensitivity, and possibly racism can be seen in the 1995 AZT trials among 12,211 women in five African countries, Thailand, and the Dominican Republic. In an effort to find a cheap and effective way of preventing HIV-positive women from passing on the virus to their babies, the CDC, National Institutes of Health (NIH), the World Health Organization (WHO), and the U.N. decided to run a test involving a control group that was given a placebo instead of the zidovudine (ZDV, previously called AZT), which had already been proven to be effective in the U.S., cutting the transmission of the virus from mother to child by almost two-thirds. The deliberate withholding of a known and effective treatment for HIV transmission meant that over 1,000 babies might have become HIV-positive unnecessarily (Munson 463-465).

The Tuskegee and ZDV abuses are not aberrations. The American medical community has exhibited an outrageous disregard for ethics when the poor, powerless, and those of color are involved. For example, a shocking series of radiation experiments were carried out since World War II on those who are vulnerable. In the 1940s, Vanderbilt University exposed 800 pregnant women to radiation to determine its effects on fetal development. From 1946 to 1956, 19 mentally retarded teenaged boys were fed radioactive iron and calcium in their breakfast oatmeal in order to test their effects on metabolism and nutrition. In 1966, the University of Cincinnati, using research funds partially from the Department of Defense, subjected a woman with colon cancer to 100 rads of full-body radiation to determine how much radiation military personnel could withstand. From 1963 until 1971, 67 inmates at the Oregon State Prison had their testicles exposed to X-rays to determine the effects on sperm production. These radiation experiments only became public in 1993 when an investigative reporter from the Albuquerque Tribune discovered 18 patients who had been subjects of such experiments (Munson 466-467).

These abuses demand an ever-vigilant re-examination of professional ethics and personal responsibility among medical researchers, clinical practitioners, and biotech engineers. They also

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[4] Even as the Tuskegee patients became blind, insane, or died, they were told that they were receiving treatment for their diseases. When the 1938 National Venereal Disease Control Act required that treatment be given, these human subjects had treatment withheld. Participants seeking treatment at local clinics were turned away. At least 50 participants were exempted from the draft during World War II, so their conditions would not be detected and treated by military doctors. Even after the conviction of Nazi doctors for experimentation on human subjects without informed consent led to the Nuremberg Code, the Tuskegee study continued. As late as 1969, a review board at the Centers for Disease Control (CDC) believed that treating the participants at that late date would do more harm than good. It was not until 1972, when social worker Peter Buxton leaked the story to the Associated Press, did the national outrage put an end to the study " (Munson 255-257).

[5] The Tuskegee Experiment was a secret to the participants, but not to the Public Health Service, the CDC, Congress, nor the community of practitioners who read reports of the study in the prestigious *Journal of the American Medical Association* (Munson 256). The fact that the government and the medical establishment knew about this study and considered the worth of these poor, rural, uneducated Black men as no more than laboratory animals, gives the African-American community good cause to be suspicious (Munson 255-257).

demand an affirmative outreach from the medical community to those whose trust have been violated.[6] In the spirit of the principle that those most negatively affected need to be among the most significant beneficiaries of research, Munson admonishes, "Today we must understand that ethnic minorities and women have much to gain from participation in clinical studies. As long as their participation is carefully controlled and not abused, they will be able to reap the benefits that have for too long accrued almost exclusively to White men" (Munson 299).

Rationing by Market Forces

In the biomedical context, *distributive justice* concerns the distribution of social benefits and burdens based on *relevant* respects or *substantive* principles of *fairness* (Munson 37-38). In contrast, Munson observes that, "The United States has already moved to at least a two-tier medical system in which the poor are provided with second-class care, while those able to pay receive the best care available" (Munson 809). If one has the ability to pay, either directly or through insurance, "…the very success of medicine creates the need for more medicine," according to Munson. Outpatient procedures, such as: CT scans, sonograms, endoscopic examinations, knee surgeries, and cataract operations may increase the likelihood of their use, for those who can pay. Surgery, radiation, chemotherapy, and bone marrow transplants may be used to treat cancer. In fact, many improvements in medicine and surgery make it possible to provide therapies for diseases that once would not have been treated. For example the combination drug therapy for AIDS can cost up to $20,000 a year (Munson 806).

While most people would not argue about the desirability of, or even the need for, many of these technologically sophisticated and expensive procedures for the health and quality of life of many of their fellow citizens, often the most expensive, most high-margin, and most "voluntary" procedures are the ones that take away many of the most talented physicians, research funds, and medical technology from those truly in need. If one were to look at the sensitive issues of saving severely premature babies with a utilitarian perspective, "one might argue that too much money is spent on trying to save infants who are not likely to gain significant benefits," as Munson relates.[7] The most premature infants may run up hospital bills of more than $500,000. It costs three times as much to care for an infant under 750 grams as it does to care for a serious victim in the burn unit and 20 percent more to care for such an infant than to pay for a heart transplant (Munson 136-137). As noted by Munson, some feminist ethicists question the fundamental assumptions about providing expensive drugs, equipment, and extraordinary life support expertise for the very ill. They believe that the pursuit of health could be accomplished by a more equal distribution of resources like food, shelter, security, and education to keep people healthy (Munson 53).

In addition, there are whole categories of "medical luxuries for the few" that, due to the market-based nature of the U.S. healthcare system, get more than their fair share of the scarce resources and benefits.

Luxuries for the Few: Cosmetic Surgery and Enhancement

There is an increasing acceptance of body alteration through elective procedures.[8] Separate from medically necessary reconstructive surgeries, in 2000, more than 1.3 million people had cosmetic

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[6] The mistrust of the medical establishment by African Americans is one of the factors that may have lead to their significantly low participation rate in clinical trials of new drugs. For example, it was ten years after the introduction of ACE-inhibitor beta-blockers that researchers were able to compile enough data to realize that these drugs are less effective on Blacks than Whites. Also, Blacks may have missed out on the chance to benefit from experimental treatments, such as taxon for breast cancer and antiretroviral drugs for HIV by not participating in trials that used these drugs (Munson 271).

[7] Munson is not necessarily referring to those 85 percent of premature babies who can be successfully saved and the 20 percent of who leave the hospital in a healthy condition and have no lasting major physical or mental impairment. For example, annually 287,000 babies are born at least six weeks prematurely. About 45,000 weigh less than 3.5 pounds (1600 grams). About half of the infants in the 500-750 gram range fail to survive. Approximately 25-33 percent of infants under 750 grams, and 40-50 percent between 500-600 grams, have irreversible neurological damage (Munson 136-137).

[8] While many argue that cosmetic surgery contributes to the psychological well-being of recipients, in an image-conscious society it is difficult to ignore research that suggests that good looks play an important role in job selection, marriage prospects, and general

surgery performed by board-certified plastic surgeons.[9] This represents a 227 percent increase since 1992. The most popular procedures are liposuction (229,588), breast augmentation (187,755), eyelid surgery (172, 244), Botox injections (118,452), and face lifts (70,882). Most cosmetic surgeries are performed on women, but there has also been a 141 percent increase in men receiving nose jobs since 1997. While most patients are White, they are not necessarily wealthy. For example, 65 percent of cosmetic surgery patients had a family income of less than $50,000 and they still had the procedures even though neither state nor private health insurance covers the cost of cosmetic surgeries (Slater 58).

These treatments or procedures are what Kathy Davis calls "a luxury problem" that "involves performing dangerous medical interventions on otherwise healthy bodies" (Parens 124). In a market-based system with a rapidly ageing population, such as the one found in the U.S., patients can choose these procedures for themselves, based on their ability to pay for them. In such a system, as Davis explains, the role of the regulatory bureaucracy is to reduce the risk of such procedures. However, in a socialized or welfare system, such as the Dutch examples cited by Davis, the health cares system shifts from a discussion of risks to one of medical need in the context of scarcity (Parens 126). As the Dutch experience in the 1980s demonstrates, even when cosmetic procedures are restricted to three categories – functional affliction, severe psychological suffering, and physical imperfection that falls outside a 'normal degree of variation,' – medical professionals had a hard time working with the subjectiveness of norms and patients increasingly sought cosmetic surgery for 'psychological well-being.' The effect was that so many Dutch citizens sought cosmetic surgery and its impact on the Dutch welfare system was so significant, that the government ultimately banned public funding for all non-functional or non-psychiatric cosmetic surgery (Parens 126-130).

It is time that society critically reassess, not only the criteria for public funding of elective cosmetic surgery – what Margaret Olivia Little calls "beauty by scalpel" -- but also question the morality of certain private funding (Parens 162). When this use of resources is not driven by disease or physiological dysfunction, when it is "a luxury motivated by pleasure born of vanity," as Little calls it, even in a free-market system, government and medical institutions need to provide a counter-balancing function to the shift of resources away from basic health care toward vanity, even if that means macro-reallocation of funds.

Luxuries for the Few: Assisted Reproduction

There is a *negative right* not to be prevented from reproducing, unless there are trumping factors. To that end, by 1998, more than 100,000 babies worldwide have been born through the use of Invitro Fertilization (IVF) or some other form of assisted reproduction[10] (Munson 660). The money spent on fertility-related medical services exceeds $2 billion a year (Munson 662). However, this negative right does not automatically imply an unbounded *positive right* to be provided medical assistance to reproduce by all possible means and at any unbounded social cost.

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societal reactions. Researcher Barry Harper of Guildhall University in England found that the penalty for unattractiveness on the job was 15 percent for men and 11 percent for women. Overweight women earn 5 percent less than average, especially in secretarial and clerical jobs. A study of 289 Dutch advertising firms found an association between good-looking executives, higher revenues, and business success. It is no surprise that looks help in the marriage market, but it is perhaps surprising that babies seem "hard wired" to be attracted to "prettier people." It is no wonder that the annual market for beauty products is $160 billion (Source: The Right to Be Beautiful, **The Economist**, May 24, 2003).

[9] American Society of Plastic Surgeons

[10] The procedures include gamete intrafallopian transfer (GIFT), zygote intrafallopian transfer (ZIFT), intravaginal culture (IVC), uterine lavage embryo retrieval (ULER), partial zona dissection (PZD), intracytoplasmic sperm injection (ICSI), and cytoplasic donation (CD). The financial cost of each fertilization cycle costs from $10,000 to $11,000, and most women who get pregnant go through three or four cycles (Munson 661-662).

In 1993, a 59-year old postmenopausal British millionaire businesswoman became the first successful IVF recipient when she paid Severino Antinori's clinic in Rome to transfer a donor embryo that had been fertilized by her husband's sperm (Munson 653).

In 1996 at the University of Southern California, a 63-year old woman gave birth to a healthy baby girl after IVF from a donor egg and sperm from her 60-year old husband. She became the oldest first time mother on record and the oldest postmenopausal woman to bear a child. In 1993, a 53-year old mother became the surrogate mother to her child and grandchild at the same time. She was the gestational carrier of the embryo of her son and her daughter-in-law (Munson 653).

In 1997, the McCaugheys of Iowa ran up a $1.5 million medical bill that they could not afford to pay due to the birth of seven babies. The babies were the result of fertility treatments using the drug Pergonal. However, the parents rejected the normal selective reduction procedure that would have raised the probability of healthy deliveries and a healthy mother. Though the babies were underweight, ranging from 2.5 to 3.4 pounds, with the help of over 40 obstetricians, neonatologists, pediatricians, and other specialists, the babies all survived (Munson 652).

Now would-be parents are looking to cloning as a means to have biologically-related children. There is no compelling reason to apply scarce, rationed medical research funds to the vanity of reproductive cloning. Other means of child bearing are available for most people including: IVF, related egg donation, surrogate mothers, and adoption. The number of people not able to use the above means is relatively small, in comparison to the proposed opportunity cost of medical research for reproductive cloning. The needs of existing life, with promising social potential, trump the potential needs of potential life.

Commenting on the rights to have a child, by any means necessary, is Mary Warnock, the chair of the Committee of Enquiry into Human Fertilisation and Embryology in the United Kingdom. Warnock advises that,

> " The right to have a child cannot be a right in either the legal or the moral sense; for it may be impossible for some people to conceive. However, it might well be thought that a moral right exists that one should not be prevented from having a child. I, myself, would prefer to express the relation between the infertile couple and their doctor in terms of the doctor's professional duty, which is a duty of compassion to his patients, which makes it obligatory for him to seek as far as he can to alleviate suffering. The duty in question is not so much legal as moral and professional, and it arises as part of the whole deeply value-laden institution of medicine. [However] I would deplore any tendency for people to become so much obsessed with their right to have a child, and to have it in the way they want, even with the characteristics they would prefer, that they forget the old sense of astonishment and gratitude that came with the birth of a child. But, as I have said, gratitude is something you do not feel when all you have got is what is owed" (Warnock 109-114).

Ambiguous Fairness: Transplantation

Worldwide, over 150,000 kidney transplants have been performed with 93 percent functioning after one year[11] (Munson 737). However, one must also be aware of the significant costs associated with dialysis, transplantation, follow-up medical care, and a lifetime regimen of medication. A kidney

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[11] My personal experience with renal transplantation has caused me to be an ardent supporter of the procedure. In 1974, as a college freshman at N.C. State, I was told by a doctor at Duke University Medical Center that, "At the current rate, you may not live through the semester." These were shocking words for an 18-year-old engineering student with a bright future. Why bother with college if it was likely that I would die within four months? The doctor reassured me that the limited number of dialysis machines were provided based on a Ethics Panel's considerations that included: age, likelihood of recovery, and an assessment of "potential contribution to society." I was assured that, as a bright young aspiring engineer from a major university, I shouldn't worry about not being selected. While this made me uneasy – that others less fortunate would not be selected – I was nonetheless relieved that I had a chance for life and that there was such a thing as an Ethics Committee, which made the tough decisions. With careful diet and medication, I staved off the dialysis until seven years later. Ultimately, in 1982, I received a kidney transplant from my father. I was humbled and blessed. It changed my life, and, just as the Duke physician said, I have contributed to society with engineering developments, community activism, paying taxes, being a role model, and raising children, two of whom are now upper division college students.

transplant costs about $40,000, a heart transplant costs $150,000, and a liver transplant can cost up to $300,000. Medications that cost $10,000 to $20,000 per year must be taken for the remainder of the patient's life (Munson 737). While the *U.S. End Stage Renal Disease Program* covers kidney transplants for everyone, those needing other types of transplants without adequate health insurance and those who do not qualify for public assistance must find some other way of raising money or they do without (Munson 737).

Allocating the scarce resources of perishable transplantable organs is partially the responsibility of screening committees at transplant centers.[12] Their considerations include: medical need, medical condition, age, social support needed to assist during recovery, whether the patient is likely to adhere to a strict lifetime regimen of antirejection drugs, ability to pay, and whether the patient is a member of the constituency that the center is committed to serving. While race and gender are not supposed to enter into the decision, *social worth* may be taken into account (Munson 742-743).

The concept of social worth, one's education, occupation, accomplishments, and potential contributions to society, are attempts at rational non-biased utilitarian prioritization of medical resources.[13] After all, if scarce resources or expensive procedures are to be allocated to anyone, why should alcoholics, drug abusers, those with poor health habits, those who are unlikely to take their antirejection medications, and those who are likely to be drains on public funds be considered equally with those more '"socially worthy"?

This exposes a deeply troubling conflict of social values. If all people have equal worth, then, as Kant would have it, social worth has no role in allocation. If alternatively, one looks at the hard decisions that maximize the benefit of the contribution made by the organ donor and the likely social contributions to be made by an aspiring youthful recipient, the utilitarian use of social worth is a valid and valuable way to make an emotionally tough decision. With all of the money wasted on cosmetic and augmentation procedures, for the sake of the vanity of the rich, why must we make such tradeoffs based on worth? While one might agree to lower the priority of one who clearly is self-destructive and who is likely to waste a precious resource, why should people have to die because they don't meet an American middle-class definition of "worth"?[14]

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[12] These committees, similar to the one I experienced at Duke, are made up of surgeons, nurses, social workers, psychologists, ethicists, and sometimes clergy. They determine whether a candidate should be admitted to the transplant waiting list.

[13] Just as I was evaluated by Duke's committee for scarce dialysis machines, if it came to that, this utilitarian approach seems heartless, but it is a way to interject and weigh the overall needs of society against the costs of treatment. After all, no doubt the Duke committee would have seen an 18-year old honor student, who worked in community activities, was a (then rare) African-American engineering student at one of the South's largest engineering schools (in which Blacks were also very rare in 1974) as a better opportunity for successful conformance to the medical regimen, as a better potential contributor to society's future, and as one whose longevity would be enhanced in comparison with the ageing, indigent, obese, multisymptomatic (many had diabetes), uneducated, and all too often self-destructive patients I observed in the waiting room.

[14] I am the "poster boy" for utilitarianism. Yet, I feel ambivalent. Why me? Many members of my own family would have fallen below me on the list, if these criteria were used. Is it survivor's guilt or a feeling that something else is wrong with the medical allocation system? On a personal note, I remain ambivalent about my history as a beneficiary of medical resources. I was poor and Black in a South that was not too far from its past legal segregation. Had I not exceeded the academic expectations of southern whites, had a family support structure, graduated from college to a professional position with a major corporation in Cincinnati that had excellent health and disability benefits, and shown an ability to stick to a lifetime of prescriptions, I may not have been selected. But does that make me better than others on the list? When it came time for the transplant in 1982, I came to the table (literally) with a living donor-related kidney from my father, while others died waiting for the right tissue match. Indeed, I believe I have contributed significantly to society with 25 years of taxes, community volunteer work, role modelling to youth, putting innovating high-tech products on the market, advising leaders of the greatest corporations of our era, writing books and articles to provoke creative thinking about social problems, educating and raising three children, trying to be a good husband to my wife, and taking care of my elderly mother. I believe the committee decisions at Duke and later at the University of Cincinnati have paid off.

New Therapies Controlled by an Irrational Few

New developments in understanding the genome and the genetic engineering that follows it also raise issues of fairness, equity, and justice. But more importantly, genetics raise fundamental issues of appropriate uses of technology. For example, similar genetic procedures can be applied for therapeutic uses and for genetic enhancement. This latter category is also thought of as *positive eugenics* and has been almost universally criticized by biomedical ethicists. As Walter Glannon states it,

> "Genetic enhancement's aim is to improve one's phenotypic traits and thereby raise one's physical or mental functioning above normal adequate levels for persons. This is significantly different from genetic testing and termination of embryos and gene therapy, not only because its aim falls outside the goal of medicine and health care, but also because it is motivated by perfectionism rather than by beneficence and justice. Medical and moral reasons for genetic intervention have more weight at and below the baseline of adequate functioning and less weight above the baseline. This is because the weight of the reasons supporting claims to receive treatment is proportional to the needs of people making their claims, and enhancements do not pertain to people's needs but to their preferences above the critical level where their basic health needs have been met. In fact, many would say that, as a program of positive eugenics, genetic enhancement is antithetical to beneficence and justice precisely because of the pervasive social inequalities that would result from its practice on a broad scale" (Glannon 77-78).

While Glannon echoes the sentiments of the majority of the biomedical community when it comes to positive eugenics, the potential beneficial impact of genetics is also being slowed by the confusion in the political arena between positive and *negative eugenics*.

The political and religious beliefs of the few are preventing the potential benefits of important new therapies for the many. The most tragic impact of the politically charged and religiously emotionalized issues of abortion and cloning is their chilling effect on legitimate biomedical research for therapeutic purposes. Though most responsible medical researchers and lawmakers reject human cloning on serious safety and eugenics bases, the cloning debate is unfortunately wrapped up in the mistaken belief that the clone of an individual will grow up to be an exact copy of that individual.[15] The public believes genetic identity results in exact similarity (Munson 649). To compound the issue, biomedical research into high-potential therapies require cloning stem cells from aborted embryos, thus the thirty-year battle over abortion further complicates the issue.[16]

We stand today in a state of research stasis. Due to the Kass Commission's make-up of a large number of people who held the same pro-life religious and moral views, and its 2001 recommendation to the President of a four-year moratorium on therapeutic cloning as part of its ban on reproductive cloning, biomedical research is unable to pursue legitimate benefits of embryonic stem cell research for therapeutic purposes in the United States, if public funds are involved (Kass, **Report of the President's Council**). At a first glance, Kass makes an elegant emotional argument against scientific research into

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[15] Therapeutic cloning is more accurately called *somatic cell nuclear transfer*. It involves removing the nucleus from an egg and replacing it with DNA from a cell from the body of a donor. This creates a cloned embryo that is genetically similar to the patient. These stem cells have the ability to transform into mature cells, such as heart, muscle, nerve, spinal cord, or kidney cells. Because the genetics are identical to the donor, it is hoped that organs can be grown and transplanted with no threat of rejection. However, with therapeutic cloning, the stem cells would be harvested by the sixth day, thus destroying the cloned embryo (**Stanford Report**, October 2, 2002). The cloned embryo is never implanted in the woman's uterus, and therefore has no chance of developing into a cogent human being.

[16] Although over a million abortions are performed every year, Americans remain divided on its moral acceptability. Even the conservative Justice Rehnquist's opinion in the 1973 *Roe v. Wade* decision, acknowledge that the state cannot place limits on a woman's decision about abortion during the first trimester (twelve weeks), making abortion on demand during this period legal and certainly giving no notion of personhood to a six day old embryo. In fact, it is not until the eighth week that even the most rudimentary brain activity is detectable. As such, President Clinton signed an executive order permitting the use of tissue from aborted fetuses to be used for research purposes (Munson 61-77). However, the Bush Administration has reversed the progress, or at least stalled the research, in cloning for therapeutic purposes by following the recommendations of its White House Bioethics Council led by the University of Chicago Ethics Professor Leon Kass (Kass, **Report of the President's Council**).

cloning for both reproductive as well as therapeutic purposes in his 1997 article *The Wisdom of Repugnance* and its follow-up 2001 article, *Preventing a Brave New World: Why We Should Ban Cloning Now*.[17] However, the arguments' weaknesses center on the emotional appeal and his "slippery slope" doomsday scenarios. Kass does not provide any compelling logical argument or any room for limited research under strict oversight. He weighs the potential positive benefits of therapeutic cloning for millions of lives already here as being equal to, and certainly no more compelling than, the potential harm done to a potential human being in a petri dish. As one who has been the beneficiary of a kidney transplant,[18] Utilitarians might find Kass and his commission repugnant for putting *deontological*[19] dogma ahead of *consequential*[20] reality *(See End Note I for further discussion).*

In order to take some of the emotionalism out of the debate, let us examine the logic of therapeutic cloning according to utilitarian or consequentialist theories.[21] Most members of the Kass Commission are likely to agree with John Noonan's assertion that conception, as the instant of parental genetic code transfer, is the decisive moment of humanization (Noonan 51-59). As such, a zygote would be considered a person worthy of full moral rights and protections. They would also believe that, as an incompetent non-autonomous person, the parents and the state have an obligation to protect the rights of the unborn embryo (Beauchamp 98-101). On the contrary, a rational scientific observer is likely to agree with Mary Anne Warren's criticism of Noonan's confusion between genetically human cell clusters and a morally human person. Warren argues that a fetus, at any stage of development, but certainly at the early stage required for embryonic stem cell research, exhibits none of the five traits of personhood and should not be accorded the full rights of personhood.[22] Warren's five traits may be an extreme test of personhood, but in either case, since the embryo at such an early stage of development cannot live outside the womb, it, at best, is no more than a "potential person" whose rights are outweighed by the rights and needs of an "actual person" (Munson 96-104).

Most scientists and ethicists agree that there seems to be no overwhelming trumping factor in favor of reproductive cloning, since other alternatives are available to infertile parents and their right to reproduce is not unqualified and unbounded. However, Kass' argument of "do no harm" assumes that the embryo, even one destined to be destroyed as a leftover from IVF treatments, has the same rights as a fully developed human. Worse, as Nobel Laureate Paul Berg observes, Kass and his commission ignored ways to regulate research, such as registering the researchers, oversight committees, peer review, research databases, and jail terms for offenders (Shwartz, Paul Berg interview 2-3). As Berg notes, "Let's prohibit attempts to clone a person, but by god, let's not cut off the possibility for capturing the benefits of this technology for treating millions of people's diseases" (Shwartz, Paul Berg interview 3).

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[17] Kass argues against cloning for reproductive purposes because: (1) the aggregate effect of asexual reproduction would change basic human relationships, perhaps in an irreversible way, (2) it could lead to the eugenics of a "perfect baby," (3) it might place despotic demands on the child, (4) it harms a potential human life, and (5) it is generally accepted as repugnant, regardless of our ability to cogently explain why (Kass, *Wisdom* 1-7).

[18] As a successful long-term recipient of a related-donor kidney transplant, I am very supportive of continued biomedical research for therapeutic purposes. Therefore, when Kass, and others such as Stanford's William Hurlburt place the potential of my life, and others like me, on the same level as a laboratory blastocyst, I am deeply offended and ask for a more logical analysis of the ethics of therapeutic cloning.

[19] See McGinn. *Ethics, Science, and Technology,* pp 3-9.

[20] See McGinn. *Ethics, Science, and Technology,* pp 3-9.

[21] Consequentialism looks at the morality of actions based on a balance of good and bad consequences. It tries to maximize the balance of positive value over disvalue (or, as Beauchamp and Childress note, the least possible disvalue, if only undesirable results can be achieved). An act utilitarian looks at practices that, over time, maximize the overall welfare of society. It allows society to override some individual property and autonomy rights, if doing so maximizes everyone's interests (Beauchamp 340-348).

[22] Warren's five traits of personhood are: (1) consciousness, including the capacity to feel pain, (2) reasoning, (3) self-motivated activity, (4) capacity to communicate, and (5) self-awareness (Munson 101-102).

There is a compelling reason to pursue therapeutic cloning (somatic nuclear transfer) to better understand the genetic makeup of disease and to research whether reject-free transplantable organs can be grown in the laboratory. This positively impacts millions of people, and is a better use of scarce medical research funds. It does the most good while minimizing the most harm. There may be indirect positive benefits to reproductive cloning as well. If indirect benefits to reproductive cloning occur as a result of therapeutic cloning research, there is no compelling reason to prevent use of this research to further advance reproductive cloning.

Toward Fairer Macroallocations of Biomedical Resources

We have the research, knowledge, and technology that would enable a fairer distribution of medical benefits. But, we may not have the collective will nor accept the personal responsibility to do so. (*See End Note II for further discussion.)*

Many of today's bioethical controversies can be traced back to an archaic set of assumptions regarding the rights of stakeholders. These rights often were developed at a time when the economic, social, and environmental conditions made their individual applications less of a problem than today. We live in a society that rapidly diffuses technology, each with intended and aggregative unintended consequences on the well being of society, to an increasing number of rights claimants who each exercises the maximalist uses of technology. This ultimately leads to the destruction of the commons and degrades the overall social fabric. As such, the rights of stakeholders must, at a minimum be bounded by the constraints of the modern technological society and, in certain special cases, be restricted. Stanford's Robert McGinn argues that,

> "An acceptable theory of rights in contemporary technological society must be able to take on board the implications of their exercise in a context in which a rapidly changing, potent technological arsenal is diffused throughout a populous, materialistic, democratic society. Use of such a technological arsenal by a large and growing number of rights holders has considerable potential for diluting or diminishing societal quality of life. Indeed, insistence on untrammelled, entitled use of potent or pervasive 'technics' by a large number of individuals can be self-defeating, e.g., by yielding a state of social affairs incompatible with other social goals whose realization the group also highly values"[23] (McGinn, *Technology*, 14-15).

The time has come to reconsider the unbounded and maximalist uses of medical technology and expertise for nonessential, elective, vain luxuries, such as cosmetic surgery, body augmentation, extraordinary life-support, and technologically extreme measures devoted toward reproduction. According to McGinn's criteria, such treatments:

- Detract resources from the well-being a global society dominated by the poor,
- Further attracts the best expertise away from non-profitable, non-glamorous, and non-cutting edge medical careers that are no less needed by the bulk of humanity,
- Engenders a massive financial cost that is subsidized by the poor, public research, tax breaks, and insurance,
- Devalues the worth of individuals to what is purely financial, and most importantly
- Allows the very real threat of global pandemics to fester in a delusional sense of security.

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[23] In cases where unbounded rights of a pre-technical era are extended to individuals and their actions, in aggregate, harm society, McGinn builds a convincing case for restricting those rights (McGinn, *Technology*, 14-15). Among the conditions for restriction are:

1. If the very existence of society is called into question
2. If continued social functioning is threatened
3. If some natural resource vital to society is threatened
4. If a seriously debilitating financial cost is imposed on society
5. If some significant aesthetic, cultural, historical, or spiritual value to a people is jeopardized, or
6. If some highly valued social amenity would be seriously damaged

(See End Note III for further discussion.)

A raging debate centers on what can be done globally to alleviate disease, provide a fairer distribution of research benefits, and minimize the threats that accompany new research. Farmer calls it "an awesome responsibility to prevent the inequalities from being embodied as adverse health outcomes" (Farmer 282). A revised hierarchy of material principles of distributive justice would enable a more just distribution to a globally needy underserved population.[24] Traditional philosophical approaches suggest allocation of scarce resources based on (Beauchamp 228):

1. To each person an equal share (egalitarian)
2. To each person according to need (beneficence[25])
3. To each person according to effort (cost effectiveness)
4. To each person according to contribution (scientific utility)
5. To each person according to merit (social utility)
6. To each person according to free-market exchanges (libertarian)

"Most societies invoke several of these material principles in framing public policies, appealing to different principles in different spheres and contexts," according to Beauchamp and Childress, however, in the United States, it seems that an over reliance on fee-market exchanges has led to a defacto allocation scheme internally, and a denial of resources and services to those external countries and cultures who cannot afford to pay inflated, profit-oriented, U.S. market rates (Beauchamp 228-229). This conflicts with the well-established sense of justice and fairness espoused by Rawls. In a *Rawlsian* society, differences in wealth and social position can be tolerated only when they can be shown to benefit everyone and to benefit those who have the fewest advantages, in particular. A just society, according to Rawls, is not one where everyone is equal, but one in which inequalities must be demonstrated to be legitimate. In addition, in a Rawlsian society, everyone must be given a genuine opportunity to acquire membership in a group that enjoys special benefits (Munson 22-23). The implications of Rawls' principles are that: (a) everyone is entitled to health care, (b) inequalities in the health care system can be justified only if those in most need can benefit from them, and (c) to the degree that the previous two conditions are not met, as in the current system, a wholesale reform is called for that would provide health care to those who are unable to pay (Munson 24-25).

A more globally fair distribution might be based on the following hierarchy of principles and assumptions, in this explicit order:

1. Egalitarian. If resources are still constrained, then…
2. Social utilitarian. If resources are still constrained, then…
3. Scientific utility. If resources are still constrained, then…
4. Individual beneficence. If resources are still constrained, then…
5. Cost effectiveness. If resources are still constrained, then and only then…
6. Libertarian, especially as it relates to treatments in support of individual desires…then
7. Lottery, as a tie-breaker

According to Munson, it is reasonable to hold that Rawls' principles can be used to restrict access to certain kinds of healthcare.

> "If someone wants cosmetic surgery to change the shape of his chin and has the money to pay a surgeon, then he may have it done. But if medical facilities or personnel should become overburdened and unable to provide needed care for the most seriously afflicted, then the society

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[24] *Distributive justice* concerns the distribution of social benefits and burdens of health care. It seeks to ensure that people receive that to which they are entitled. Philosophical theories of justice attempt to resolve questions of distributive justice by providing explanations as to why distinctions are made in any unequal distribution of benefits and burdens (Munson 37-38).

[25] *Beneficence* requires that physicians act in ways that promote the welfare of the patient. It is not enough to 'do no harm;' a physician must proactively seek to work on behalf of the patient's best interests (Munson 34-35).

> would be obligated to forbid cosmetic surgery. By doing this it would then increase the net access to needed health care by all members of society" (Munson 25).

Under Rawls, as well as the *Harm Principle* and the *Welfare Principle*, the rich would not be permitted to exploit the poor who need basic health care.[26] But, perhaps a better solution in the real world of capitalism is not to forbid cosmetic surgery or other luxury treatments, but to tax them heavily. California already imposes a luxury tax on automobiles over $30,000 and charges vehicle license fees on a sliding scale based on the value of the car, in a recognition of the burdens cars place on the environment. We do not prohibit Hummers; we tax them. We also tax the lifestyle demons, such as liquor and tobacco, based on their long-term medical burdens on society. Why not tax face lifts, tummy tucks, nose jobs, breast enhancements, colored contact lenses, surrogate mothers, IVF for post-menopausal women, age-sterile men, and homosexual couples who insist on biological reproduction instead of adoption? Tax them heavily, 100 percent or so, and provide those benefits to the 4 million Americans how go without any treatment, the 60 million underinsured Americans, or contribute the funds to the World Health Organization for the 1 billion people who have no access to clean water.

Another principle that would work toward making treatments available globally on a fairer cost basis is to require pharmaceutical companies to adhere to what Farmer calls a '*uniform ethic*' in return for the extraordinary privileges granted to their industry by society. Since the pharmaceutical industry benefits from publicly funded research, government-granted patents, and tax breaks, and since it makes products vitally important to public health, it should be accountable to society at large, rather than just to its shareholders. Farmer argues for this uniform ethic as a condition for entry into any national and international marketplace (Farmer xxvii).

The profession also needs to use more rational decision criteria, rather than religious dogma, that balance beneficence and autonomy with a 'qualified' utilitarian approach to decision-making about allocation of scarce resources. Society needs to be comfortable with the Oregon prioritization of Medicaid spending that placed very low-weight premature infants under 500 grams at a ranking of 708 on a list of 709 items (Munson 138). When it comes to extraordinary means to prolong life, a human being in a permanently vegetative state is not a person in a relevant moral sense, and as such, as Dan Brock states in his argument in favor of limited euthanasia, "…once death has been accepted, it is often more humane to end life quickly and peacefully, when that is what the patient wants" (Brock 218). Likewise, Munson cites an effort of the Massachusetts Task Force on Organ Transplantation, which recommended guidelines to mitigate the need for a strict utilitarian approach to allocation. Their report included:[27]

1. Transplant surgery should be provided to those who can benefit from it in terms of probability of living for a significant period of time with a reasonable prospect for rehabilitation.
2. Decisions should not be based on "social worth" criteria.
3. Age may be considered as a factor, but only to the extent that age is relevant to life expectancy and prospects for rehabilitation.
4. If not enough organs are available for all those who might benefit from them, final selections should be made by some random process, such as a lottery, or a first-come, first-served basis.

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[26] Under the *Harm Principle*, society may restrict the freedom of people to act, if the restriction is necessary to prevent harm to others. The *Welfare Principle* holds that it is justifiable to restrict individual autonomy if doing so will result in providing benefits to others (Munson 43-45).

[27] This "qualified, bounded, utilitarian approach" feels more appropriate. As a transplant recipient, I feel that I would have still had a good opportunity to receive a treatment and ultimately a transplant from the regional medical centers, Duke and the University of Cincinnati, near where I lived at the time. My ability to pay by the luck of a good employer-based insurance plan would have been irrelevant. My life expectancy, post treatment, made the investment a fair trade-off for society. And, if all other things were equal, I would have accepted the fairness of a sequential waiting list or lottery. In all of these factors, my life would have been respected as one worth saving, but I would not have unfairly eliminated others from the same opportunity.

5. Transplants should be provided to residents of New England on the basis of need, regardless of their ability to pay, as long as it does not adversely affect health care services with a higher priority. Non-residents of New England can be accepted after they can demonstrate an ability to pay for the procedure (Munson 743).

Likewise, the promise of therapeutic cloning is so great and the 4,000 genetic diseases are so serious that Munson and Davis believe that, "It would be wrong to give in to the objections that have been raised to gene therapy. This outcome would be as wrong and almost as serious as if we had failed to develop the use of antibiotics or vaccines" (Munson 632). The ethical principles one might employ in a more logical, consequential analysis of the therapeutic cloning debate might include:

- Research done only in settings with strict oversight
- Research that is meant to maximize the life-enhancing values, rather than the vicarious unbounded rights of reproduction
- Use fetal tissue that is already planned for destruction and ensure that no financial gain is involved for the donors
- Parallel use of adult stem cells for embryonic research
- Informed consent of the donors
- "Do no harm" applies to sentient beings, not a group of cells that cannot live on their own
- Existing life trumps potential life

As even Senator Orrin Hatch, a man noted for his conservative politics, observed, "Look, as far as I'm concerned, right-to-life means giving life an opportunity to tens of millions – not worrying about the fate of a small, undifferentiated clump of cells in a petri dish" (Shwartz, Paul Berg interview, 11).

Conclusion

Many people try to conveniently ignore the plight of the masses of humanity, as if their diseases will never reach the rest of us. For example, Garret Hardin, in *Lifeboat Ethics*, maintains that we have a duty not to help the poor and starving of other countries because they will overrun the lifeboat and sink us all. This short sightedness assumes that we live in isolation and presumes that the fates of those in the lifeboat are independent of the fate of those in the water *(See End Note IV for further discussion).* Others claim that aid does not work, that bureaucracies tend to perpetuate themselves at the expense of the poor, and that aid creates an unhealthy dependence, in the manner described in the Biblical parable of teaching the poor to fish rather than giving them fish. We ignore these people at our own peril. HIV-AIDS, tuberculosis, SARS, and plague are vivid reminders that the plights of the most remote citizens are shared by all. According to Farmer, "Complex social webs not only link the city and countryside but also link one country to another. An estimated one-third of U.S. tuberculosis cases occur among those born in another country, and this population is growing. The ways in which tuberculosis is transmitted mean that a local outbreak constitutes a global concern" (Farmer 277).

On a purely utilitarian argument, Peter Singer argues that we ought to seek to reduce the overall amount of suffering in the world, even at great cost to those of us who have more affluent lifestyles (Singer). While Henry Shue argues that everyone has a positive right to minimal subsistence, i.e., one that imposes obligations on the others to assist in meeting this right, the over-reliance on the Libertarian market based allocation of food and medical resources seems to constrain society's abilities to provide a just distribution of medical services and benefits to those most in need (Shue). As Farmer keenly observes it, "If there is no role for any but profiteers, what sort of health care environment have we created?" (Farmer 279)

"It does not require a clever brain to destroy life. In fact any fool can do that.
But it takes brains – and extraordinarily brilliant brains to create conditions for human happiness
and to make life worth living."

- Kwame Nkrumah

Speech at the Academy of Sciences, Accra, Ghana
November 30, 1963

End Notes

I. Comments on the Historical Antagonism between Religion and Science

I remain very wary of deontological, or deity ordained, approaches to ethics. In fact, Christian theology and secular science have been antagonistically and emotionally opposed throughout much of Western history. For hundreds of years, the medieval Church set up a series of obstacles to scientific inquiry including: attributing disease to demons; sanctioning and profiting from the supposed healing powers of the relics of the Christian martyrs; using the Apostle's Creed and its belief in the resurrection of the body to outlaw dissection in medical schools; promoting ideas that abasement adds to the glory of God, that cleanliness was a sign of pride, and that filthiness was a sign of humility.

Throughout European history, schools of thought contrary to Church teachings were seen as blasphemous, and appropriate punishment was doled out. Prodded by St. Bernard, conservative theologians from Paris, Orleans, and Lyon hounded the masters of Chartres and summoned them to appear before a tribunal to face charges of heresy for teaching a scientific view of the intrinsic creative powers of nature – a view that threatened the 700-year-old doctrine of nature as the passive object of God's creation (Goldstein 69-70).

This was the same mentality that burned at the stake Giordano Bruno in 1600 for uttering and publishing the heresy that there were other worlds and other beings inhabiting them (Sagan, **Cosmic** 185). Staunch religious dogma was the reason for the Catholic hierarchy's imprisonment of the aged Galileo Galilei for proclaiming that the Earth moves (Drake 330-351). Johannes Kepler, after whom the laws of planetary motion are named, was excommunicated by the Lutheran Church for his uncompromising individualism on matters of doctrine and because of his writing of *The Somnium*, in which he imagined a journey to the moon. In addition, Kepler's mother was dragged away in a laundry chest in the middle of the night to be burned as a witch for giving birth to such a heretic and selling herbs (Sagan, **Cosmic** 50-71).

The conflict between knowledge-based science and belief-based religion confront our intellect, challenge our deeply ingrained value system, and tear our social fabric. Although each has its own dogma of fundamentalism or scientism, respectively, this conflict between diametrically opposed views of the world has been, and continues to be, a major obstacle to holistic human progress. For example, during the 1721 breakout of smallpox in Boston, even though Zabdiel Boylston's inoculation technique was proven to produce a lower mortality rate than inflicted by the natural disease, it was widely opposed by the medical establishment as unsafe, and by the church as an interference with God's will (Tucker 17-18). In the case of modern "right-to-life" advocates (antiabortion activists) and the conservative opposition to therapeutic cloning, the critics seem to employ the worst-case scenarios that pander to fear and subjective "revulsions." In fact, many of the same social results can occur through natural childbirth and child rearing.

II. Professional Responsibility

Who bears the responsibility for implementing solutions? After all, when the threat of biological genocide due to a genetically engineered mutant virus having escaped a pharmaceutical laboratory confronts humanity, who is to blame? Are research scientists or politicians the culprits? Those whose education or tastes have confined them to the humanities protest that scientists alone are to blame. Scientists say, with equal contempt, that humanists, politicians, and the 'commercializers' cannot wash their hands of blame because they have not done anything to help direct a society whose ills grow worse from, not only error, but also inaction (Bronowski, 5).

Do scientists and physicians have a responsibility to the global society, beyond their immediate institutions and clientele, and if so, what is that responsibility? Humanity's needs, wants, and desires are realized through *technology*,[28] which in the biomedical sense is the clinical practice. After all, the traditional idealized argument has been that it is not the knowledge of the genome that scares us; it is its application that plays on our paranoia. We have been encouraged to believe that it is one thing for

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[28] *Science* in its purest sense is a semi-neutral activity. Scientists search for truth and as a result get neutral facts. It is *technology* that draws upon our biases.

the biologist to know how to perform gene splicing, but it is quite another for biological engineers to actually create harmful forms of life. Therefore one might be tempted to conclude that research biologists and clinical practitioners bear most of the responsibility for solving the equitable distribution of medical benefits. Do they?

This debate around the role of scientists and engineers as ethical social agents has been around for ages. Nearly fifty years ago, Bronowski reinforced the basic argument that scientists have a responsibility to humanity. Bronowski stated that the dilemma of today (1956) is not that human values could not control a mechanical science. It was the opposite: "The scientific spirit is more human than the machinery of governments." Being human, however, means that scientists can no more shirk their responsibility to improve our lot than politicians. His argument, that scientists have a crucial responsibility (for which they are uniquely trained) to make the public fully aware of the implications of their work, should serve to bring the 'overly tunnel-visioned' researcher back into the realm of political activist and citizen. According to Bronowski, no longer do scientists have a right to hide behind the veil of scientific neutrality. They must participate in decision making as full partners with the public.

III. Revisiting Scientific Ethics

In more recent times, Stanford professor Robert McGinn described several ethical problems facing modern 21st Century practitioners. While McGinn's assessment was applied to a broader range of engineers and scientists than the scope of this paper allows, it is reasonable to extend some of his ethical concepts to biomedical researchers and to clinical practitioners, as a group. These problems include execution problems, such as unfair distribution of benefits and costs, the fear of whistle blowing, and lack of consideration of long-term effects. He also described communication problems, such as fraud and misrepresentation of scientific research (McGinn, Ethics 18-26). Scientists and physicians have also erred by having misplaced loyalties. Some have become servants to institutions rather than the public. For far too many in the biomedical community, the basic canons of professional ethics have been subverted to gain employment and to preserve power structures.

The ethical issues go beyond prevention of institutional and business abuses, one must demand a higher standard of those who are carelessly irresponsible practitioners, who participate in unnecessary human experimentation, who attempt to clone humans, and those who patent new forms of life and new means of food production. Since we live in a world whose interconnected systems threaten to spin out of control, we must collectively ask the biomedical community, "Are you living up to the proper codes of ethics or have you delegated your responsibility to business interests and government ideologues?

In the past the actions of individuals or single industries or even single nations mattered little to the outcome of the world. Modern biomedical technology is quantitatively more pervasive in western society and leads to quantum changes in the qualitative influences on human life. We have a whole new generation of microbes and chemicals that can influence the future of the planet. With this established, scientists and physicians must go back to their professed ethics. From this perspective, they must be part of the decision-making process.

Scientists and physicians, as a group and as individuals, have special responsibilities as citizens, which go beyond the public at large. "All citizens have an obligation to devote some of their time and energies to public policy matters. Minimal requirements for everyone are to stay informed about issues that can be voted on, while stronger obligations arise for those who by professional background are well grounded in specific issues as well as for those who have the time to train themselves as public advocates," as put forth by Philosopher Mike Martin and Engineer Roland Schizinger (Martin 29l). Their loyalty needs to be to humanity, not just to their employers or their governments. We have seen that their professions support this concept (at least verbally).

Traditional professional society codes of ethics cite a series of actions and practices that a physician or scientist should not engage in. It is a "thou shalt not" approach to ethics. Citing what one cannot do is tantamount to applying a deontological top's down approach to ethics.[29] McGinn's moral responsibilities provide a paradigm shift away from merely cost reduction or harm

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[29] Most codes are so general that they rarely give the practitioner any tangible guidance as to how research and development should be performed and the deontological admonitions give the practitioner a mistaken belief that, perhaps, one can perform any task that is not explicitly prohibited. To this end, Stanford's Robert McGinn has identified a series of Fundamental Moral Responsibilities (FMR) that provide a much more concrete and proactive approach to engineering ethics (McGinn, *Moral Responsibilities* 6-19). Those FMRs include:

- FMR1 – Not act in any way that one knows (or should have known) will harm (or pose an unreasonable risk of harming) the public interest.
- FMR2 – To try to prevent (or prevent the repetition of) preventable harm (or the creation of an unreasonable risk of harm) from being done to the public interest.
- FMR3 – Assure that all parties likely to bear non-trivial risks from one's work are adequately informed about them upstream and given a realistic chance to give or withhold their consent to their subsequent imposition.
- FMR4 – Work to the best one's ability to serve the legitimate interests and objectives of the patient or institution.

From these FMRs, there are certain Derived Moral Responsibilities (DMR) advocated by McGinn that include:

- Disclose to the institution or patient any unrecognised options, reduction to a combination of maximization of benefits within the context of minimizing harm. From a quantitative analysis perspective, McGinn is proposing the optimization of two simultaneous equations (Anderson 350-352, 372-373):

- *Maximax* – Select the decision that maximizes the maximum payoff (do the most good for the most people).
- *Minimax Regret* – Minimize the maximum regret, or opportunity loss, associated with a decision (do no harm).

This is an improvement over traditional approaches that minimize harm (regret) or maximize profit (payoff), but rarely attempt to do both.

IV. Observations from Alfred North Whitehead Regarding Cooperation vs. Competition

Our biomedical technology is causing social changes at a tremendous rate. Research scientists and physicians have a history of cooperation on their side. They can be the vanguard of a total international movement to save humanity. If they do not, our lease on the future may be unrenewable. The great scholar Alfred North Whitehead delivered a series of lectures in 1925 in which he warned us of the danger of non-cooperation.

> "During the past three generations, the exclusive direction of attention has been a disaster of the first magnitude. The watchwords of the nineteenth century have been struggle for existence, competition, class warfare, commercial antagonism between nations, and military warfare. The struggle for existence has been construed into a gospel of hate. However, successful organisms are those that modify their environment so as to assist each other. A species of microbes that kills the forest also exterminates itself.
>
> In the history of the world the prize has not gone to those species which specialized in methods of violence, or even in defensive armour. In fact, nature began with producing animals encased in hard shells for defense against the ills of life. It also experimented with size. But smaller animals, without external armour, warm-blooded, sensitive, and alert, have cleared these monsters off the face of the earth. Also, the lions and tigers are not the successful species. There is something in the ready use of force, which defeats its own object. Its main defect is that it bars cooperation.
>
> Every organism requires an environment of friendship. The Gospel of Force is incompatible with a social life" (Whitehead 259).

Humans would fare much better if we follow the lessons of nature. Cooperation and a moral use of our non-neutral biomedical technology are the key ingredients to the success of the human organism. Enlightened scientists and physicians might teach us this lesson. It is reasonable to contend that the scientific ethic is the doctrine that should be embraced as an idealized goal and that physicians and other biomedical practitioners can be the agents of success. As we embrace the idealized ethics of science and medicine, one needs to walk down this path with a clear understanding of limits, biases, and a neo-consequentialist view of the social implications of biomedical innovation. One hopes that renewed emphases on ethical decision-making and just distribution of benefits might be accompanied by professional codes of ethics with 'teeth.'

Regardless of the organizational path, scientists and physicians who insist upon declaring themselves neutral or focused only on their immediate communities are, in effect, unethical. As that 1960s mantra succinctly stated, "If you are not part of the solution, you are part of the problem."

- Help the institution or patient reach a clarified definition of problems originally presented to the practitioner in distorted form,
- Ensure that all prerequisite conditions for the safe operation of a technology transferred from a more to a less developed society are satisfied,
- Be wary of paradigm overshooting as regards the use of analytical methods in innovative scientific contexts,
- Establish a precautionary organizational culture as regards the formal approval of integrity-related developments and/or treatments,
- Assure that in work akin to social, medical, or technological experimentation, that human subjects likely to be put at risk of harm are informed about those risks and given a meaningful opportunity to give or withhold consent to their imposition.

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