The 2014 Inaugural University of Miami Bioethics Bowl

Case Packet

(Adapted from the 2013 National Undergraduate Bioethics Conference Case Packet)





Case 1 - An Obligation to Adopt?

The earth's population recently passed 7 billion. Although it took many thousands of years for the population to reach 1 billion people, the last billionth was added in just over a decade (1). Although no one knows exactly how many people the world can sustain, we do know that there are already far more people than could be supported at the level of the affluent first-world. In fact, if everyone consumed resources at the rate that the average American does, we would need more than four additional earths to sustain the population (2).

In addition, a higher population adds to environmental concerns such as global warming (3) and to issues of global justice, as is suggested by the amount of resources required for the wealthy first world. Every person added to the population, then, contributes to a growing problem. We might also worry about the situation into which we bring newly-created people. The threat of global warming suggests that the coming years may be challenging, and a growing population means fewer resources for everyone. The procreative act brings into existence a new person who will suffer if things go badly (4).

All of these considerations seem to demand that we think deeply about the morality of making new people. Most of us, however, do not. Despite these fairly common observations about population and environmental concerns, and worries about the harms that may befall future generations, many of us plan families, often for the simple reason that we want children. And indeed, raising children and forming a family can be an intensely valuable and rewarding experience.

There is one last consideration, however, which seems clearly morally relevant, and which is not often acknowledged. Yes, many of us want children, and want to form families, but there is more than one way to have a child and to make a family. In particular, one could adopt. Even more particularly, one could adopt a needy child. And the need is great. Currently, conservative estimates tell us that there are more than *sixteen million* adoptable orphans in the world, and many of these orphans will endure much suffering if not adopted (5).

The situation is thus as follows: There are moral concerns about bringing a new person into existence, both because of what it will mean for the new person, and for us. In addition, there are literally *millions* of children who desperately need parents. Many of us want to parent children. A solution seems to recommend itself: Have prospective parents raise the needy children. No new people are created, the hopeful parents get children, and the desperate children get parents.

Question: Could it be then, that morality recommends adoption? Is it possible that we are even obligated to adopt? How do we balance the above considerations with the overwhelming intuition that we are morally permitted to have children?

⁽¹⁾ Nyerson, William R. "Population: The Multiplier of Everything Else." The Post Carbon Reader Series: Population. 2010.

⁽²⁾ Global Footprint Network. 2011. National Footprint Accounts, 2011 Edition.

⁽³⁾ Cohen, Joel. "Population and Climate Change," *Proceedings of the American Philosophical Society*. VOL. 154, NO. 2, June 2010

⁽⁴⁾ Benatar, David. Better Never to Have Been (Oxford University Press, 2006).

⁽⁵⁾ USAID, UNICEF, and UNAIDS, Children on the Brink 2004: A Joint Report on Orphan Estimates and A Framework for Action, p. 4 (2004).

Case 2 - Hazardous Waste Siting

In 1990, a proposal was put forward for the siting of a low-level radioactive waste dump in upstate New York. The proposal caused concern outside of the immediate area because two of the five potential disposal sites were in one of the primary dairy-farming areas in the state.

At that time, 600 million pounds of milk per year were shipped to consumers in urban areas all over New York from farms within ten miles of the two proposed waste sites. Citizens far and wide were worried: radioactive contamination of the ground water could have devastating effects, not just on residents of the small towns where the sites were planned, but on a milk supply that spread all through the tri-state area. But such decisions are not always brought to such a high level of public scrutiny. The potential impact to people living in more wealthy and politically-empowered communities raised red flags and garnered media attention in this case, but often such siting decisions are driven by a desire of policy-makers—conscious or unconscious—to minimize public blowback by situating waste sites where the communities affected are those least likely to raise a fuss, often because they are lower-income, more poorly-educated, or otherwise inured to unfair treatment by being members of traditionally underprivileged groups, such as racial minorities.

Nuclear waste is a byproduct of hospitals and other health facilities, which use radioactive material for a variety of functions. Proponents of the waste sites emphasized the utility of such a radioactive dump to the local medical community. Many procedures involve such radioactive compounds: radiation from cobalt and powdered cesium is used to sterilize blood and medical equipment, while cobalt is also used to kill diseased brain tissue. Capsules of cesium are implanted next to tumors to kill cancerous cells, and thin tubes of radioactive material are used to operate gauges and other diagnostic devices (1). Lack of access for disposal of such material presents, not only a significant financial burden to the hospitals, but often limits the type of technology and amount of waste-generating procedures that are then possible at each facility—which corresponds to a lower standard of care for citizens served by them, including the very same politically disempowered groups mentioned above.

Yet as a 1990 editorial noted, "78 percent of the so-called 'low-level' waste's radioactivity will be generated by nuclear power plants—much of it highly toxic and long lived—with most of the balance from industrial sources. Disposing of this waste in a New York State-owned and operated dump will primarily benefit nuclear utilities and industry, not the medical community, as some would have us believe."

Adapted from a New York Times editorial, "Upstate New York Nuclear Waste Sites Endanger Milk Supply," by David Sprintzen, originally published March 2, 1990, accessed January 17, 2013.

Question: How could the needs of the various affected communities—local residents, dairy consumers in the tri-state area, perhaps even the dairy cows themselves—have best been met (and respected) by policy- makers in this case?

^{(1) &}quot;Hospitals become a major source of radioactive waste," *Natural News*, http://www.naturalnews.com/025711_waste_hospitals_store.html#ixzz2IIhJ31pj, accessed 17 January 2013.

Case 3 - Epidemics and Drug Testing

ABC Pharmaceuticals produces Antibe, an antibiotic approved for use in the US, but only for those who are severely ill, because it causes liver and joint damage in 5% of those who take it. Like most medications, it has never been tested on children. (It is difficult to do an ethical trial involving children, and the drug companies fear lawsuits if children are injured.)

When a meningitis epidemic broke out in Africa, the company used the opportunity to test Antibe on children there. Meningitis kills about 10% of its victims, and leaves about 15% with neurological damage (hearing loss, paralysis, mental disability). Since the epidemic struck a very poor area, most of the children would go untreated. ABC saw a chance to provide humanitarian relief, reap some good publicity, and determine whether Antibe was safe and useful for children.

The research design had two arms. In one, children received Antibe. In the other, they received the standard treatment. Children were assigned randomly to one arm or the other. As is the case with many "standard treatments," the evidence supporting this one was only moderately persuasive. Desperate parents brought in their sick children. Doctors and nurses speaking the patients' native languages explained the study, and got written or spoken consent.

Question: Was ABC justified in taking advantage of this epidemic to test its drug on children?

Case 4 - Global Baby Making

Over the previous several decades, the amount of technological intervention available to assist reproduction has become rather astounding. In addition, the world-wide-web and the advent of outsourced 'labor' have generated new possibilities for gamete provision and sales and for locating willing surrogates. These developments have now come together to offer potential parents the opportunity for a truly globalized baby-production process that includes Internet sperm and egg sales as well as outsourced gestation (1). Consider the case of Sam and Rachel.

Sam and Rachel are a committed lesbian couple who wish to start a family. Neither woman wants to gestate a baby, and after much discussion, they decide that they would rather not have a child that is genetically related to just one of them, as that would be unfair. In addition, they would prefer not to adopt. So instead, they utilize an online gamete-provision service (2) in order to select a sperm and egg for fertilization; although they admit that it makes them feel a bit shallow, they acknowledge that they choose the gametes based on the donors' "looks, athleticism, intelligence and success (3)." After all, they say, shouldn't good parents want the best for their child?

After selecting an egg and sperm, the egg is fertilized in vitro, and the embryos are frozen and shipped to India where the couple's chosen fertility clinic has located a surrogate for Sam and Rachel (4). The purchased embryo is then implanted in the surrogate, who becomes pregnant on the first attempt. A few weeks before delivery is expected, Sam and Rachel excitedly travel to India, where they vacation while waiting for the surrogate to go into labor. Once they get the call that the baby is coming, the happy couple goes to the hospital and pace nervously while the surrogate delivers their baby. Upon delivery, the baby is whisked away from the Indian surrogate and delivered to Sam and Rachel. Although the process is difficult for the Indian woman who gestates and delivers their baby, she is grateful for the opportunity, as she earns over \$6,000 dollars for her services, which is more than she would make in ten years of working at her normal job. And Sam and Rachel are grateful to the Indian woman, as they pay only about 20% of what a surrogate would cost in the US (5). Shortly after the birth, Sam and Rachel return home with their child to begin their new lives as a family. Although the case of Sam and Rachel is fictional, it could easily be real, and all of the individual aspects of the case occur regularly.

Question: Is there anything morally wrong with this kind of globalized baby-production? If everyone involved benefits from the arrangement, is there any moral reason to oppose it?

⁽¹⁾ As featured in Zippi Brand Frank's film, Google Baby.

⁽²⁾ Such as NWCryoBank (https://www.nwcryobank.com) or Tiny Treasures (http://www.tinytreasuresagency.com).

⁽³⁾ For a look at the ways in which desirable traits interact with the availability and cost of women's eggs, see the controversial article "Will You Be My Baby's Mama? The egg donor market wants you, Harvard women, and it'll pay" in Harvard's student paper *The Crimson* (http://www.thecrimson.com/article/2004/4/29/will-you-be-my-babys-mama/). (4)Like the Akanksha Infertility Clinic, run by Dr. Nayna Patel (http://www.ivfcharotar.com/surrogacy_services.php).

⁽⁴⁾ Like the Akanksha linerthity Chinic, run by Dr. Nayha Fater (http://www.ivicharotar.com/surrogacy_s

⁽⁵⁾ Statistics taken from the *New York Times*, "Surrogate Pregnancy Goes Global," http://www.nytimes.com/2010/06/16/arts/television/16google.html

Case 5 - Chemical Corridor

There is an 85-mile stretch of the Mississippi River extending from Baton Rouge to New Orleans in Louisiana unofficially known as "Chemical Corridor." The area is heavily industrialized, hosting numerous oil refineries, petrochemical plants and factories.

The construction of Standard Oil's Baton Rouge refinery in 1908 signaled the beginning of development in the lower Mississippi River chemical corridor; its flood-proof site, on high terraces near the head of navigation for ocean-going ships, offered ready access to crude oil and natural gas, ample water for industrial processes, and a giant sink for wastes, in addition to the favorable winter climate. Other refiners and chemical manufacturers quickly followed Standard Oil's lead, and there was an accelerated program of federal investment during World War II. By 1947 there were 177 refineries and chemical plants in Louisiana, and their numbers continued to grow: 211 in 1962, 284 in 1981, and 320 in 2002. Along the lower Mississippi River, the number of oil-refining and chemical-processing plants rose from 126 in 1962 to 196 in 2002. A landscape once dominated by sugarcane fields had been thoroughly transformed (1).

The EPA's Toxic Release Inventory cites literally tons of chemicals released into the environment along this stretch of the river. Whereas on average 7 pounds of pollutants per person are released into the air in the United States, for the mostly poor and black people living along this part of the river, there are 2,277 pounds of pollutants per person. The state of Louisiana averages 21 pounds per person, and two-thirds of all of Louisiana's toxic substances released into the environment are released here. Anecdotal evidence suggests that the incidence of several diseases, including cancer and asthma, is inordinately high among the human communities in this area. As John McQuaid notes, it's hard to get a clear answer on the question because it butts up against the limits of epidemiology and environmental science. That uncertainty touches on deep public anxieties, as well as broader issues, including public access to health data, government regulation, legal liability and the efficacy of applying results of animal tests to humans (2).

Recently a manufacturer of polyvinyl chloride (PVC), a common plastic used mostly for pipes, was considering installing a plant here that would be a significant polluter but, under threat of legal protest, decided instead to build it in a less poor community, removing a potential source of more contamination but taking much-needed jobs with it.

Question: Should private companies be held liable for the negative externalities of their business practices? How is your response affected with reference to the lack of clear, scientific, evidence on the health effects of these business practices?

⁽¹⁾ Colten, Craig E., (2006 January) "The Rusting of the Chemical Corridor," Technology and Culture, 47(1).

⁽²⁾ McQuaid, John, (2000) "Cancer Alley': Myth or Fact?" The Times-Picayune, May 23.

Case 6 - Global Organ Transplant Tourism

Organ transplantation is one of the medical miracles of the 1900s; however the supply of available organs, especially for kidneys, falls very short of the demand. Traveling to another country to receive a lifesaving organ transplant is called "transplant tourism." In 2004, the World Health Organization, called on member states "to take measures to protect the poorest and vulnerable groups from transplant tourism and the sale of tissues and organs, including attention to the wider problem of international trafficking in human tissues and organs (1)."

Insurance companies have been financing transplant tourism. In 2007, an insurance alert appeared in the July issue of a prominent American medical journal. This alert named American companies such as IndUShealth, based in Raleigh, N.C., which refers transplant patients to India, as well as United Group Programs in Florida, which offers an internationally accredited hospital in Thailand for kidney, heart, lung and liver transplants using both living and deceased donors. Blue Cross of South Carolina also began to cover transplants that take place in Thailand, and there are probably other insurance companies, as well as other states that would consider similar programs. Furthermore, patients in West Virginia can receive a 20% rebate from the State Government for traveling overseas to have an organ transplant. At least five national and international bodies have strong and longstanding objections to transplant tourism including The World Health Organization (WHO) and the United Network for Organ Sharing (UNOS), the nonprofit hired by the U.S. federal government to handle most transplant matters in the United States.

Transplants taking place in developing countries, with developing economies, carry a lot of risk. These risks include medical risks, coercion in the buying and selling of organs, and the exploitation of the poor. The buying and selling of organs is illegal in the United States under federal law (2), however many people argue that a compensated and regulated market based system for living kidney donation would work. In Iran, kidney transplant waiting lists were eliminated in 1999, after the country adopted a quasi-regulated and compensated living-unrelated donor renal transplant program in 1998. The Declaration of Istanbul (3) contains many principles related to organ trafficking and human rights. One such principle (Number 5) is reproduced below:

5. Jurisdictions, countries and regions should strive to achieve self-sufficiency in organ donation by providing a sufficient number of organs for residents in need from within the country or through regional cooperation. (a.) Collaboration between countries is not inconsistent with national self- sufficiency as long as the collaboration protects the vulnerable, promotes equality between donor and recipient populations, and does not violate these principles. [Emphasis added] (b.) Treatment of patients from outside the country or jurisdiction is only acceptable if it does not undermine a country's ability to provide transplant services for its own population.

Question: Is organ transplant tourism "ethically problematic?" While the buying and selling of organs in the United States are currently illegal, are global market systems for body parts ethical?

⁽¹⁾ World Health Assembly Resolution 57.18, Human organ and tissue transplantation, 22 May 2004, http://www.who.int/gb/ebwha/pdf_files/WHA57/A57_R18-en.pdf.

⁽²⁾ National Organ Transplant Act of 1984

⁽³⁾ Steering, C. O. T. I. S. (2008). Organ trafficking and transplant tourism and commercialism: the Declaration of Istanbul. *Lancet (London, England)*, *372*(9632), 5-6.

Case 7 - Climate Change and Burning of Fossil Fuels

Climate change refers to the rise in global average temperature that has been observed in the last few centuries. During roughly the last 50 years, this rise has been attributed to human activities of burning fossil fuels and deforestation. Climate change will impact populations differently across the planet. Some regions will experience increases in extreme weather events like flooding. Other regions will experience longer growing seasons. Climate change, then, will impose a number of costs but also produce new benefits for people everywhere.

A key problem is that many of the populations who will suffer many of the costs are in developing countries. These countries have not contributed to or benefited from the burning of fossil fuels that is responsible in part for recent climate change. These countries have the need to grow their economies like industrial countries by engaging in the same kind of energy production that led to industrialization. It is also the case that present generations in industrial countries did not choose to contribute to climate change; previous generations did.

Question: Should all countries incur costs associated with burning fossil fuels in order to mitigate the rise in global average temperature, which would then keep developing countries poor? Or, should current generations in industrial countries cut their fossil fuel emissions, while allowing developing countries to emit as much as they need to in order to achieve economic growth?

Case 8 - Allotransplantation & The Affordable Care Act

Each medical innovation has its own driving force. Is it to improve patient care? To save lives that otherwise would be lost? Or is it primarily for the self-aggrandizement of an investigator or the financial goals of an institution? "Allotransplantation" is transplantation of the face, limbs, etc. It is now possible to formulate protocols that use either very light immunosuppression, or no immunosuppression at all in performing these transplants (1). Without the heavy burden of immunosuppression, this type of transplantation can become worthwhile. Non-life sustaining or non-lifesaving transplants, such as a hand or face transplant can have the result of both altering the physical appearance of a patient and enhancing their abilities to interact socially. In addition, doctors have claimed that putting a new hand or face on someone is astounding: it changes the morphology of the brain, which can be observed with functional magnetic resonance imaging.

The extreme expense of heart, liver, kidney, and other lifesaving transplants doesn't necessarily raise questions about their value; however expenses associated with non-lifesaving or non-life sustaining transplants may be a different story. Limited resources (financial and medical) raise questions about the medical necessity of these procedures. We could see non-lifesaving or non-life sustaining transplants available only to those people who can pay for them out-of-pocket. We could also see insurance companies begin to offer special body part replacement, or some other type of specific transplantation insurance.

The Affordable Care Act (2) ensures that health plans offered in the individual and small group markets, both inside and outside of the Affordable Insurance Exchanges, offer a comprehensive package of items and services, which are known as essential health benefits. *Essential health benefits must be covered by certain plans starting in 2014.* Essential health benefits must include items and services within at least the following 10 categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care.

Question: Should non-lifesaving or non-life sustaining transplants (hands, limbs, etc.) be added as an essential health benefit under the Affordable Care Act?

⁽¹⁾ Starzl TE. Immunosuppressive therapy and tolerance of organ allografts. *New England Journal of Medicine* 2008; 358:407–411.

⁽²⁾ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, §2702, 124 Stat. 119, 318-319 (2010).