REGIONAL
ETHICS BOWL
CASES

FALL 2014

Prepared by:
Michael Funke, Chair
Susanna Flavia Boxall
Rhiannon Dodds Funke
Gretchen A. Myers
Adam Potthast

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**Case 1: Suspended Animation**

A Pennsylvania hospital will be testing out a new emergency technique in the upcoming months on patients who are dying but not yet dead. The technique will be tested on ten patients who have gone into cardiac arrest after suffering a knife or gunshot wound. Attempts to restart their heart will have failed. The patient's chest will be open and they will likely have lost approximately half of their blood. Their chance of survival will be less than seven percent. At this point, the team of doctors prepared to implement the new technique will be called in.

The patients' blood will be replaced with a cold saline solution that quickly cools the body, stopping almost all cellular activity. The solution will first be pumped into the heart and brain, then into the rest of the body. Within about fifteen minutes, the patient's temperature will drop to 10 degrees Celsius. In this state, cells need less oxygen and doctors have more time (up to two hours) to repair the patients' wounds. After the injuries are treated, the patients will warm back up as the saline solution is replaced with blood.\(^1\) The survival rate of these test patients will be compared to a control group of patients who met the same criteria but were not treated with the new technique.

The technique was developed by Doctor Peter Rhee, who has successfully tested it on pigs. Indeed, in a 2000 study, ninety percent of the pigs who had been suspended were revived—while all of the control group pigs died. Further, the revived pigs did not show any signs of physical or cognitive impairments.\(^2\) As Rhee explains, "If a patient comes to us two hours after dying you can't bring them back to life. . . But if they're dying and you suspend them, you have a chance to bring them back after their structural problems have been fixed."\(^3\)

The technique sounds very promising. But even David King, one of the surgeons that has worked on animal tests and helped prepare the technique for human trials, admits that it is "way, way out there." "The scientist in me would be very careful promising anything for a salvage therapy for the most desperate of all situations. You can't expect miracles," King states.\(^4\)

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Due to the nature of this technique and the type of patients needed to test it, it will be impossible to get their informed consent. Requiring consent is important when medical research is performed on human subjects and this standard is typically maintained even in emergency situations. The hospital has attempted to notify the community that the trial is taking place by holding discussion groups and placing advertisements in the newspaper. People are able to opt out online, but no one has done so yet.


Case 2: Soylent Hunger

Half of the world’s population (approximately 3 billion) is poor, while a third is so impoverished that it lives on the brink of starvation – i.e., unable to meet its most basic survival needs. The projected increase in world population over the next few decades (2 billion) suggests that famine will become ever more pervasive. A proposed solution to this problem is to mass-manufacture and distribute a drink called “Soylent.”

Developed by a software engineer as a substitute for more costly whole-foods meals, Soylent is a thick, beige liquid designed to provide the body with all the necessary nutrients, and “[a]t around $3 per meal, the product could be a real money saver for some people.” Because Soylent does not spoil, it could be transported to underdeveloped countries with greater ease than fruits and vegetables. Citing a lack of phytonutrients, some experts remain skeptical about the ability of a drink comprised of 30 ingredients to satisfy the body’s daily nutritional needs. As Walter Willett, chair of the nutrition department at the Harvard School of Public Health, acknowledges, people could survive on Soylent, but they may not have optimal function. Still, Soylent’s creator claims that his product could help ameliorate “many issues around food aid and security.”

Quite apart from the lack of a comprehensive study confirming Soylent’s supposed ability to nourish the body, the cultural consequences of replacing a whole foods diet with a shake produced in the industrial West may be problematic. An anthropological perspective on food reveals that food is not just another commodity: it is “life giving;” it involves farming, which in turn “means rural livelihoods, traditions and cultures...[and] agrarian histories.” Moreover, not all famine is created equal: the anatomy of hunger and food insecurity in Southern Mexico will not be identical to Zimbabwe’s. For this reason, food security activists and researchers have favored local (not imported) solutions to endemic famine.

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Case 3: Victim's Dilemma

It is important that neighbors, roommates, families and others who cohabitate get along reasonably well and in ways that often exceed normal legal requirements. For example, it is perfectly legal to have mid-day shouting matches with a roommate, but there is a profound social harm to engaging in such behavior regularly. Shouting matches are not only bad for roommates, but also a nuisance for the neighbors. In response, some municipalities have passed so-called nuisance laws. One such law passed in Norristown, Pennsylvania allows police officials to pressure landlords into evicting a tenant if police are called three or more times in four months.

Though the law was intended to minimize the reliance on police for minor, non-violent domestic disputes, the possibility of eviction caused at least one woman to put herself in harm’s way. Lakisha Briggs was stabbed in the neck with a shard of glass by her ex-boyfriend, Willbert Bennett, and she refused to call police for fear that she would be evicted. Briggs had previously called the police on three other occasions due to Bennett's volatile and at times violent behavior. After he was arrested the last time, the responding police officer told Briggs: "You are on three strikes. We're gonna have your landlord evict you." After Bennett was released from jail, he returned to Briggs' apartment and demanded to move in. Fearing that she and her three-year-old daughter would be evicted, Briggs allowed Bennett to enter and stay. Soon the relationship turned sour and during a fight Bennett stabbed Briggs. A neighbor saw her bleeding and called the police when she refused to do so.

The Norristown law attempts to preserve neighborhoods and encourage people to settle their differences without burdening police; however, it has had serious unintended consequences. In response to Briggs' filing suit against the borough through the ACLU, Norristown has modified its "disorderly behavior" ordinance. The newly adopted law provides that the city can levy fines on landlords when tenants repeatedly call the police in situations that "do not require a mandatory arrest to be made."

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16 City Code, Borough of Norristown, PA, Montgomery County, http://ecode360.com/11550747
Case 4: Smokin' Ride

It’s probably a good idea not to smoke in a car with children. However, in an increasing number of states ranging from Arkansas to California, it is also against the law. While laws vary from state to state and there is no federal law, one can be fined up to $250 if stopped for a traffic offense and found to be smoking with someone younger than 18 years old in the car.

If the law works and fewer people smoke in cars with their children, the health benefits are clear. Tobacco smoke is especially dangerous to children, because their lungs and brains are still developing. In closed spaces like cars, children can inhale a level of secondhand smoke that can rise to unhealthy, even dangerous or poisonous levels. Adults can avoid secondhand smoke in most places by opting not to go to bars, restaurants, or houses where people are allowed to smoke. However, unlike adults, children riding with parents frequently cannot opt to get out of the car or find alternative transportation. Whether they complain about the smoke or not, they are essentially trapped in a car with a smoking adult, unable to choose an alternative.

There are no health upsides to smoking in a car with children. However, restricting personal behavior in a private automobile has some worried about infringements on personal freedoms. For instance, eating food, talking on the phone, and listening to audiobooks all distract drivers and potentially put children at risk. While the effects are not as pronounced as smoking-related illnesses, some argue that the rationale for this law would allow police to fine someone for listening to Little House on the Prairie with children in the car. And some wonder why such a rationale needs to stop at a car. Smoking in one’s home with children is also extremely detrimental to their health. If the laws against smoking in cars with children pass muster, why couldn’t a law fine parents for smoking in a private residence? If children’s wellbeing is at stake, why not penalize parents for bringing home junk food, fast food, or for exposing their children to large amounts of television?

While these worries about liberty are real, they do not seem to phase support for laws against smoking in cars with children. According to the University of Michigan C.S. Mott Children’s Hospital National Poll on Children’s Health, 82% of adults support such

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18 For additional information consider: http://ash.org/carsmoking
laws. Enforcement should not be a problem, says Vermont State Police Lt. Gary Scott, “It’s going to be difficult to figure out how old the kid in the car is, but if you see a car seat in the car and the operator is smoking there’s grounds to at least stop the vehicle and they can investigate from there what’s going on in the car.”

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Case 5: Stealing Pets

In 2013, Judy Camp saw something that shocked her: her neighbor was keeping his dog (an Australian cattle dog named “Duke”) outside on a four foot chain in temperatures that were set to dive below freezing for several nights. This wasn’t the first time she’d seen the dog, which her neighbor claimed was being kept as a guard dog and treated as such, outside in miserable conditions. Other neighbors had complained to the police about possible neglect of the dog. Some states and municipalities have so-called “anti-chain” laws that prevent chaining dogs outside for a certain amount of time, but Camp’s town of Okanogan, Washington isn’t one of them. The police had visited, but judged that the dog was being adequately fed, so they didn’t intervene.

That night, Camp decided she had to do something drastic, and stole Duke from the chain. She brought him inside and after the weekend took him to the veterinarian. At the veterinarian the dog was found to be stolen and Camp had an altercation with the police. She was charged with stealing the dog and obstruction of justice. If she’d been found guilty on all charges, she could have faced $5000 in fines and three years in jail.

While there are laws against animal cruelty and animal neglect, dogs are considered property under the law and cannot be taken from their owners without their owners consent. The law gives dog owners a large degree of latitude in how they treat their dogs. However, Camp saw her action as a rescue from awful conditions that overrode the rights given to Duke’s owners.

In March a jury acquitted her and in the mean time she had offered $500 to the dog’s owners for Duke and her offer was accepted. She was convicted only of obstructing justice and paid a fine as well as doing 100 hours of community service.

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Case 6: Destroying Wildlife To Save It

In the Pacific Northwest and Northern California, which is the habitat of the rare spotted owl, the Fish and Wildlife Service has authorized the shooting of 3600 barred owls. The barred owl is not a threatened species and is protected under the Migratory Bird Treaty Act.26 These more aggressive owls are believed to be the cause of the spotted owl’s near-extinction. Though the Fish and Wildlife Service came to its decision with the help of biologists and an ethicist, Friends of Animals (an advocacy group) is suing to stop the killings. According to Michael Harris, Legal Director for Friends of Animals, it is preferable to “allow these species to either figure out a way to coexist or for nature to run its course.”

A similar quandary has arisen in New York. The mute swan - a majestic bird that glides on many of New York State’s lakes and ponds - may be intentionally exterminated by 2025. Though visually striking, the mute swan is an invasive species and has altered the native ecosystem. The proponents of eliminating the swans claim the birds destroy the vegetation on which other species feed, and may be responsible for the dwindling population of black terns. Still, the State of New York has had to face several critics. David Karopkin, founder of GooseWatch, explains that in 1970 there were 1000 swans in New York, while today there are 2200 - hardly the explosive growth that one might expect of a species labeled “invasive.”27 Though Karopnik is not a swan-fan (he notes swans’ aggressive nature), there are many who are. Defenders of the mute swan have collected signatures to keep the swans in place and have argued that, if the State of New York wants to prevent habitat-destruction, it should focus its energies on human development.

However, the most strident outcry over the destruction of wildlife as a means for conservation was elicited by the auctioning of a permit to kill a black rhino.28 The highest bidder was an American hunter, who paid $350,000 to kill one of the last 5,000 remaining black rhinos in the world. The purpose of the auction was to raise a large sum of money for rhino conservation in Namibia, whose national commitment to wildlife conservation is inscribed in its constitution. Though it is clear that a large influx of cash could positively impact the preservation of black rhinos, the auction has encountered widespread criticism. Anthropology professor Barbara King has called for “compassionate conservation,” which stresses the intrinsic value of each individual member of a species. Likewise, Dr. Mark Bekoff, an expert in animal emotions, criticized

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the philosophy underlying these conservation efforts: “Killing animals to save others sets
a bad example and a regrettable precedent and is not the way to foster peaceful
coeexistence.”29

29Marc Bekoff, “Black Rhino Auctioned in the Name of Conservation,” Psychology Today, January 12,
name-conservation
Case 7: Personnel Business

Brendan Eich developed the coding language JavaScript and helped found the Mozilla Foundation, an open source wing of Netscape. In 2005, Eich became chief technology officer of Mozilla Corporation, the foundation's profit making arm. In 2014, Eich was made CEO. After eleven days, Eich resigned under pressure from employees, consumers, and board members. Eich was forced out because of his support for California's Proposition 8, a ballot initiative to change the state's constitution to include a provision that "only marriage between a man and a woman is valid or recognized in California."30

In California, donations to ballot measures in amounts above $100 are public record and the LA Times published a list of contributions for and against proposition 8. Eich contributed $1,000 to the campaign in support of restricting marriage to between one man and one woman. 31 According to Eich, his support for Prop 8 stems from a personal religious commitment and was separate from his role as CEO. Before his ouster, Eich tried to assuage concerns writing, "I am committed to ensuring that Mozilla is, and will remain, a place that includes and supports everyone, regardless of sexual orientation, gender identity, age, race, ethnicity, economic status, or religion."32

Proponents of marriage equality and gay rights advocates called for a boycott of Mozilla's flagship product, Internet browser Firefox. Internet dating site OKCupid answered the call for boycott by blocking Firefox users from the site. When customers using Firefox attempted to access the site they received a message that read in part, "Hello there, Mozilla Firefox user. Pardon this interruption of your OkCupid experience. Mozilla's new CEO, Brendan Eich, is an opponent of equal rights for gay couples. We would therefore prefer that our users not use Mozilla software to access OkCupid."33 According to many, this is an example of free speech being used effectively to combat intolerant speech.

However, some journalists are "questioning whether the episode undercuts the well-groomed image of Silicon Valley as a marketplace of ideas and diversity of thought, and whether, in this case, the tech world surrendered to political correctness enforced through a public shaming on social media."34 Andrew Sullivan, a prominent advocate for

marriage equality has objected to Eich's treatment writing, "When people’s lives and careers are subject to litmus tests, and fired if they do not publicly renounce what may well be their sincere conviction, we have crossed a line. This is McCarthyism applied by civil actors. This is the definition of intolerance."35

Case 8: Cholera in Haiti

After a magnitude 7.0 earthquake, Haiti was in dire need of international help. Already a poor country to begin with, Haiti needed much more than aid to rebuild its economy and infrastructure. It needed help on the ground to prevent a massive humanitarian crisis that would arise if its people couldn’t get food, water, and shelter. In response to Haiti’s need, peacekeepers from across the world poured into the country to help Haiti feed its people and rebuild. Unfortunately, that is also how many people in the country contracted cholera. More than 8000 people in Haiti died from cholera and 600,000 contracted the disease between 2010 and 2013.36

The source of the outbreak—a strain of cholera common in South Asia—is believed to be a camp of Nepalese peacekeepers who had come to the country to help Haiti rebuild and had been doing good work to get people food and shelter. Conditions at the camp were less sanitary than initially reported and it’s likely that human waste from the camp flowed into a nearby river. Cholera spread to nearby towns when people down river used the water for drinking and washing.37 The outbreak has now spread to the local region, including Cuba, the Dominican Republic, and possibly Venezuela.

When knowledge of the Nepalese camp emerged rioters at a UN base in Haiti demanded the Nepalese troops leave. These riots ended up killing four Haitians and one UN worker. Recently, a group of 5000 Haitian cholera victims petitioned the UN, calling for large sums in reparations. But the UN, citing doubts about the cause of the outbreak and the inadvisability of suing people who had come to help, invoked its privileged immunity from lawsuits in 2013. Meanwhile a law firm representing the Haitians filed suit in a New York district court.

Haitians suffering or dying from cholera need some kind of recourse, but it also seems ungrateful to some people to ask for damages from people who had come to help. If the Nepalese peacekeepers were at fault for the origin of the epidemic, they most likely did not intend to transmit the disease. The mission to Haiti was to help alleviate suffering and rebuild the nation. If there is a more noble goal, it would be hard to find one. While duties of care and caution cannot be ignored, if individuals and countries must worry about unintended side effects of peacekeeping missions, then deployments will become much more complicated and contingent. Some countries may choose not to deploy peacekeepers at all rather than risk being sued for hundreds of millions of dollars for an unforeseen consequence like the transmission of a disease. Many more may look for immunity from litigation or propose increasingly difficult contractual arrangements.

Case 9: A Child's Right to Die

A law recently passed in Belgium allows certain terminally ill children to choose euthanasia. For the law to apply, a child must not only be terminally ill but also close to death and in great pain. The child must be able to show that he or she understands the consequences of his or her decision, the child's parents must consent, and the child's medical team must approve. The Belgian law is the first of its kind without an age limit, though the Netherlands has a similar law that applies to children over twelve. And even though euthanasia for adults has been legal in Belgium for over a decade, some people believe the new law goes too far.

Protestors argue that children simply cannot make such difficult decisions and that modern medicine can alleviate much of an ill child's pain. As one newspaper put it, "Belgium has allowed the killing on demand of terminally ill children and has headed for the ethical abyss. A state which allows something like this is a failing state." Religious leaders believe the law is immoral: "The law says adolescents cannot make important decisions on economic or emotional issues, but suddenly they've become able to decide that someone should make them die," one Belgian archbishop commented. And backlash has been especially harsh abroad: for example, the chairman of Forbes Media went so far as to suggest that allowing euthanasia for children would put us "on the malignantly slippery slope to becoming a society like that envisioned by Nazi Germany, one in which 'undesirables' are disposed of like used tissue."

Protestors point to stories like that of Godelieva De Troyer to support their opposition. De Troyer died two years ago. She was 64 years old and in perfect physical health. She was also severely depressed. She emailed her son, Dr. Tom Mortier, to tell him she was looking into euthanasia. He assumed that her doctors would never allow it because she was not physically ill. But only three months after her email, Dr. Mortier got a call at work informing him that his mother had been euthanized. He was completely enraged, and has since become an outspoken critic of Belgium's euthanasia law. "This is suicide with the approval of society," he believes.

Allowing children to also choose euthanasia would only allow for more abuse. Despite this vehement opposition, the law is widely supported in Belgium. Supporters assert that it would only apply in an extremely small number of cases and that each child would have to be very clear about his or her wish to die. Indeed, only five children have requested euthanasia.

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in the Netherlands since 2002. As one Belgian Senator has noted, "What is scandalous is the suffering of sick children when they are going to die."  

Supporters point to stories like that of Danny Bond. Bond was born with a bowel disease that caused him excruciating pain. At thirteen years old, he started talking about killing himself. Indeed, he did try to kill himself three times. When his mother resuscitated him after his third suicide attempt, he told her that she had let him down by saving him. His condition worsened shortly after he turned twenty-one, and he told his parents that he wanted to die and that he wanted their help. But they knew that assisting him would be a crime. Ultimately, he starved himself to death and asked his parents to stay by his bedside to make sure that his doctors did not treat him. "All he wanted was the privilege to be given an injection that would kill him instantly in seconds, and I had to watch him die in days," his mother lamented.

Case 10: Burglerbungler

Tom has had enough! Burglerbungler, a home security service, mistakenly listed Tom’s home phone number on information they gave to customers. Instead of reaching the company to report a burglary, customers reach Tom, at all hours of the day and night. Tom called the company numerous times, requesting they provide the correct number to customers. The calls continued. Tom wrote the company numerous times, requesting they provide the correct number to customers. The calls continued. In desperation, and if it doesn’t appear that the caller is in imminent danger, Tom now handles these unwanted calls his own way. “Oh, I’m not in the mood right now. Could you call back later?” “I’m sorry, but we’re all just leaving for lunch. We’ll be back in a couple of hours.” Tom gives customers his name, provides the correct number for Burglerbungler, and suggests that they call customer service to complain about their treatment.
Case 11: It's a Shame

The meme on Facebook is a familiar one: a child or pet contritely holding or wearing a dry erase board exposing their sins. When it's the puppy who has just covered the house in toilet paper, it can be cute. No one worries about the emotional trauma the puppy suffers from such shame (even if the puppy looks as if he knows he has just committed a mortal sin). But with children, the debate continues as to whether the shame involved with mandatory social media apologies is a good way to both punish and rehabilitate the offender.

Stories of public shaming occur in the Bible, as well as historical fiction. The Scarlet Letter by Nathaniel Hawthorne may be the most famous work in literature to address public shaming as a form of punishment. In the book, Hester Prynne is forced to wear a red "A" on her chest because she gave birth to a child out of wedlock. But public shaming is not merely a historical fiction—it has actually been used in many societies and has appeared in many forms.

Public shaming has been relatively rare in our modern justice system, but some judges have made strides to return to such forms of punishment when it seems to fit the crime. For instance, in 2006, U.S. District Court Judge Donald Molloy sentenced a man to walk around the federal courthouse in Missoula, Montana, for fifty hours wearing a large print sandwich board with statements that announced his crime. The man had lied about being a military veteran in hopes of reducing charges for other crimes he had committed, so the sandwich board read "I am a liar. I am not a Marine," on the front, and "I have never served my country. I have dishonored veterans of all wars," on the back. Some find this type of punishment fitting, inventive, and effective.

Others question whether public shaming actually results in the sort of rehabilitative ends that it appears to seek. Parents who publicly shame their children, particularly for cyber-bullying, often receive criticism that they are failing to lead by example, and are giving power to the very practices they are trying to eliminate in their children. For instance, Cara Schneider was criticized for posting images on the internet of her daughter holding a sign admitting to cyber-bullying and informing the public that she was having to sell her iPad for her bad behavior. Some felt that Schneider should not be exposing her daughter to online ridicule. Others believed

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48 The full text of The Scarlet Letter can be read at http://www.bartleby.com/83/.
49 See crowd-sourced history of public shaming on Wikipedia at http://en.wikipedia.org/wiki/Public_humiliation, and review the primary sources to which the page links for historical context of public shaming.
51 "We often complain about judicial foolishness, so it is a rare pleasure to take note of at least one time when the judge got it just right," http://www.dailynterlake.com/opinion/article_6082c761-cf77-52cc-aac7-32ae0f0c2d4d.html?mode=qm, Opinion, Daily Inter Lake, July 12, 2006
that the online shaming would further alienate her daughter, preventing future positive communication and training.
Case 12: Jezebel Bounty

The Internet magazine *Jezebel* is a feminist presence on the web and has become known for a series called "photoshop of horrors." The series includes unedited versions of the photographs published by top women's magazines. Recently Jezebel offered a $10,000 bounty for "pre-Photoshop images" from writer/actress Lena Dunham's Vogue photo shoot. In short order someone produced the unedited photographs and Jezebel published them side-by-side with the significantly altered Vogue images.

Jezebel's intention in asking for and publishing unedited photographs is to expose unrealistic images of women and the dramatic distortions required to attain magazine cover beauty even for magazine cover girls. On her television show *Girls*, Dunham has also taken aim at unrealistic body images, but she described Jezebel's bounty as predicated on "faux altruism." Dunham went on to defend the Vogue images, saying "Vogue isn't the place that we go to look at realistic women, Vogue is the place that we go to look at beautiful clothes and fancy places and escapism."

Although there is clearly an element of fantasy in some of the Vogue photographs (one image has a pigeon digitally placed on Dunham's head) some argue that fashion magazine fantasies are harmful. Critics worry that digitally making models appear younger and thinner will lead consumers to internalize unrealistic and unattainable standards of what counts as normal or beautiful. Some who acknowledge these concerns still suggest that there are times when uncovering distortion misses the point that a "different" person is being featured.

In a further twist, Annie Lebowitz, the photographer who shot Dunham for Vogue, has threatened a lawsuit based on the publication of unedited versions of her photographs. This has brought critical attention to the way that Jezebel obtains photographs by paying a "bounty" to people willing to surreptitiously obtain unedited versions. Jezebel has refused to say who provided the unedited photographs, although some speculate that it is most likely a staffer at Vogue.

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53 Jessica Coen "We're Offering $10,000 for Unretouched Images of Lena Dunham in Vogue." Jezebel, http://jezebel.com/were-offering-10-000-for-unretouched-images-of-lena-d-1502000514
Case 13: Sexbots

Douglas Hines has designed what he calls "the world's first sex robot." Her name is Roxxxy. She responds to touch and can hold simple conversations. According to Hines, "The sex robot thing is marketing—it's really about making a companion." Indeed, he initially wanted to create a home health care aide for sick or elderly people but the project became mired in bureaucratic paperwork and he had to turn to other markets.58

As more and more advanced sex and companion robots are created, they may become more and more popular. Indeed, there are many potential benefits to sex robots: "users would obtain sexual fulfillment with something resembling the target of their desire (assuming you manage to find such a model), without harm. No STDs; no confusion about consent . . . ; in terms of sex work, for example, there wouldn't be a worry around sex trafficking or harm to the workers."59

And sex toys are already widely used today—are sex robots really that different than vibrators or fleshlights? Perhaps they are: "What makes robots different from sex toys, and for some people what makes them creepier, is that robots trigger us to make the opposite kind of psychological flip-flop: like a mirror-image of classic sexual objectification, robotic sexual partners encourage us to look at mere inanimate objects as sentient, conscious, willful, and desirous." Concerns arise because we have a tendency to anthropomorphize robots but at the same time we know that the robots are not in fact alive and do not have to be treated like living beings.60

The widespread use of sex robots could encourage people to withdraw from interactions and relationships with other humans in favor of robots designed to unconditionally serve them.61 Robots designed to feign intimacy could replace intimate relationships between humans that are, though real, also complicated and messy. People could act out their most perverse fantasies or violent urges on sexbots without concern for their wellbeing, and allowing such behavior with sexbots could encourage them to behave similarly toward other human beings.62

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Case 14: 23andMe (and the FDA)

International scientists working on the Human Genome Project worked for nearly a decade to decode the sequences of chemical base pairs of our DNA and learn what our genes have to say about us.\(^63\) One of the goals was to use genetic data to better understand the keys to disease and prevention,\(^64\) in addition to other scientific applications of the research in areas such as energy,\(^65\) anthropology, evolution,\(^66\) and food consumption.\(^67\) While we have made huge advances in genetic testing and are now able to look at our genes to determine parental lineage and the causes of miscarriage, some more predictive analyses are still in progress.\(^68\)

Take, for instance, the tests provided by Silicon Valley-based tech company, 23andMe. This company has made news in the past year because of its direct-to-consumer (DTC) genetic testing, which it marketed as able to predict gene variants “linked to traits ranging from ancestry and earwax to warfarin sensitivity and Alzheimer’s disease.”\(^69\) The company came under pressure from the Food and Drug Administration (FDA), and was ordered on November 22, 2013, to stop some of its marketing because of concerns about the reliability and applications of the information the company provided.\(^70\) The company since complied with the demands of the FDA and has been permitted to continue marketing its product.\(^71\) But the concerns still persist about the propriety of using such easily-accessible genetic testing to learn more about one’s genetic history and propensities.

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\(^{63}\) Robert Krulwich, Cracking the Code of Life (television show), PBS, April 17, 2001.


\(^{69}\) Benjamin Cohn and Dalga Surofczy, “Regulating Direct-to-Consumer Genetic Testing vs. The Right to Know,” [http://synapse.ucsf.edu/articles/2014/05/22/regulating-direct-consumer-genetic-testing-vs-right-know](http://synapse.ucsf.edu/articles/2014/05/22/regulating-direct-consumer-genetic-testing-vs-right-know), Synapse, May 22, 2014.

\(^{70}\) See Warning Letter to Ann Wojcicki, CEO, 23andMe, Inc. at [http://www.fda.gov/iceci/enforcementactions/warningletters/2013/ucm376296.htm](http://www.fda.gov/iceci/enforcementactions/warningletters/2013/ucm376296.htm), U.S. Food and Drug Administration, Dept. of Health and Human Services, November 22, 2013.

\(^{71}\) See Close Out Letter to Anne Wojcicki, Co-Founder and Chief Executive Officer, 23andMe, Inc. at [http://www.fda.gov/ICECI/EnforcementActions/WarningLetters/ucm391016.htm](http://www.fda.gov/ICECI/EnforcementActions/WarningLetters/ucm391016.htm), U.S. Food and Drug Administration, Dept. of Health and Human Services, March 25, 2014.
For instance, one journalist took the challenge and submitted her genes for analysis to 23andMe, Inc., and detailed her reaction to the information she received. Most prominent was the paranoia that some results caused her with regard to predisposition to diseases she had never even imagined, as well as concerns about whether she would be required to disclose her results to insurers, and a generalized sense that the information was not easily digested or accessible to the average consumer due to the complexity of the science behind the results.

Another journalist, however, found the results both entertaining and relieving, as he found that his genetic profile showed rather low propensities to many common diseases. He also encouraged others to take the test, with the warning that, "the shorter the genetic straw you draw, the more important it is for you to be aware of it." He argued that the results could help people become more proactive about their health and wellbeing. Samples of the information obtained from this journalist's report can be reviewed on his blog review of 23andMe.

Some have wondered why the FDA was involved at all. After all, 23andMe just takes a little saliva - one sends the test tube to the 23andMe lab, where it is analyzed and a report is generated. Users don't consume anything, and the procedure is completely non-invasive. However, the FDA regulated the tests as a "medical device" and demanded that the information provided to users be scientifically tested and verified.

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Case 15: Batkid

On November 15, 2013, Ed Lee, mayor of San Francisco, declared the day “Batkid day forever.” On this day, Miles Scott, a 5-year old boy who was suffering from leukemia, fulfilled his dream of being Batman for a day with the help of the Make-a-Wish Foundation and the city of San Francisco. The story quickly went viral, warming the hearts of Americans; even President Barack Obama publicly congratulated Miles for “saving Gotham.”

Bringing Miles’ dream to life, involved printing fake newspapers, staging crime scenes, closing roads, and was costly, around $105,000. Though the city of San Francisco originally footed the bill, two philanthropists reimbursed the city for its costs. While $105,000 brought happiness to a child who was experiencing a life-threatening illness, the same amount of money could have perhaps been used to much greater effect: such as buying bed nets for thousands of people in malaria-stricken regions, or preventing blindness in 100 children by providing treatment for trachoma, as Peter Singer has suggested. Given that we live in a world of limited resources, so the argument goes, shouldn’t we allocate our money to produce the greatest good for the greatest number? Or, as Singer puts it, “[i]t’s obvious, isn’t it, that saving a child’s life is better than fulfilling a child’s wish to be Batkid?”

Many readers did not find the answer to be obvious. Some claimed that, after going viral, the Batkid event likely resulted in hundreds of unexpected donations to the Make-a-Wish Foundation, and inspired people to donate to other charitable causes. Moreover, as the number of donors to charitable causes continues to decline, it might be misguided to criticize those who donate at all. While some people, like Singer, may choose their charities based on a utilitarian calculus, most Americans give to charity as an expression of deeply held values and relationships, such as “family, neighborhood, and voluntary associations.”

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75 Peter Singer, "Heartwarming causes are nice, but let’s give to charity with our heads" Washington Post, December 19, 2013, http://www.washingtonpost.com/opinions/heartwarming-causes-are-nice-but-lets-give-to-charity-with-our-heads/2013/12/19/43469ae0-6731-11e3-a0b9-249bb34602c_story.html
76 Rob Reich, "Charitable Giving and the Great Recession" October 2012