2018 National Bioethics Bowl
Case Packet

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This packet contains fifteen cases, with three questions following each case. At the National Bioethics Bowl competition, only *one* of the three questions will be selected. Teams will only answer the single question read by the moderator during for each case. Not every case will be read in the competition.

Case 1: Instructions in Ink?

An elderly man was found unconscious on a Miami street and brought to the emergency room of Jackson Memorial Hospital. His blood alcohol level was elevated. He was breathing with difficulty and showed signs of septic shock. He had no identification and no one accompanying him. On examining the patient, ER staff found the words "Do Not Resuscitate" tattooed on his chest. The word "Not" was underlined and there was something that looked like a signature tattooed beneath the last word. The attending physicians attempted to bring the patient to consciousness so that his treatment options could be discussed, but they failed. So they put the patient on an IV drip and gave him antibiotics, oxygen and adrenaline for his rapidly decreasing blood pressure, but while they considered how to proceed, they refrained from intubating him and putting him on a ventilator.

At first, the physicians were inclined to do whatever was necessary to keep the patient alive, given that it was unclear what the patient's actual wishes were. They were reluctant to embark upon an "irreversible" course of action, and they were uncertain of the legal force of the tattoo.[1] They felt that they could not be certain that the tattoo expressed the patient's current wishes or whether it was ever intended to convey a medical message at all. In one documented recent case,[2] a man with several serious health problems entered a hospital in order to undergo a below-the-knee amputation. He was found to have "DNR" tattooed on his chest. Because he was fully conscious, hospital staff were able to review his code status with him and he told them that he would want to be resuscitated in the event of a cardiac arrest. He joked that his "DNR" tattoo was the result of a lost bet he made while intoxicated and that he did not plan to have it removed because he believed no one would take it seriously. The Miami physicians may not have been aware of that particular case, but they were aware of such a possibility. As one of the physicians put it later, "We've always joked about this, but holy crap, this man actually did it."[3]

On the other hand, it seemed as if the Miami patient had gone to extraordinary lengths to convey his wishes to medical personnel should he be unable to communicate. The three words were written out fully in large, bold letters. This tattoo would be unlikely to be overlooked, while written orders might not come to light in time to preclude an unwanted intervention. Some people wear DNR jewelry – bracelets or necklaces – for just that reason. Perhaps, then, a tattooing was this patient's way of insuring that emergency personnel would be aware of his desires regarding treatment.

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[1] http://www.nejm.org/doi/full/10.1056/NEJMc1713344#t=article

[2] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3445694/

[3] https://www.theatlantic.com/health/archive/2017/12/what-to-do-when-a-patient-has-a-do-not-resuscitate-tattoo/547286/

In a quandary, the physicians asked for an ethics consultation. After review, the ethics team recommended that the staff follow the tattoo's instruction, saying they believed it to express the authentic wishes of the patient. The physicians complied with the ethics team's advice and the patient died later that evening. Afterwards, the hospital's social services department found a proper written DNR order that the patient had filed with the Florida Department of Health. The physicians involved in the case were relieved that they had taken the course the patient had wanted for himself.

Questions:

1. Did the physicians make the correct decision in honoring the tattooed DNR order?
2. What evidence should physicians weigh in deciding whether to honor non-traditional DNR orders, such as jewelry or tattoos?
3. Should the physicians have waited to act until hearing from the Florida Department of Health?

Case 2: The Real Winner

Andraya Yearwood, born a male, identifies as a girl and plans to undergo hormone therapy one day to complete her transition. In ninth grade, Yearwood changed her name and pronouns from male to female. In tenth grade, she competed as a female and immediately won two state championships in sprinting.

Her body could be mistaken for a fullback on a football team in high school; her father played football in college. When Yearwood competed in Connecticut in 2017 on her track team in high school, she won state championships in both the 100- and 200-yard dash. Because Connecticut's rules for high school athletes prohibit discrimination based on gender identity or gender expression, and because they allow teens to play based on self-identification, Yearwood competed as a female. Was this fair to the hundreds of natural girls against whom she competed? Was the real winner of the 100- and 200-yard dash the 2nd place female, Kate Hall?

Connecticut is not the only state to regulate how transgender students can compete in high school sports. Similar to Connecticut, California allows transgender students to play on the gender-based team that matches their self-identification. However, Texas requires students to participate on the team that matches the gender of their birth certificates.

Nebraska implemented a Gender Identity Eligibility Committee, composed of a doctor, a mental health professional, a school administrator, and a member of the Nebraska School Activities Association. The committee decides on a case-by-case basis whether a transgender student can compete in a gender-segregated sport. In Indiana, anatomical sex determines participation; before competing, Indiana also requires students transitioning from male to female to undergo sex reassignment surgery.

Yearwood has not undergone any hormonal treatment to begin toward sex reassignment surgery, so she retains any alleged natural biological advantages of one born male.

In 2016, the International Olympic Committee ruled that women need not undergo sex-reassignment surgery before being eligible to compete. Both the Olympics and the NCAA do require one year of taking hormone-replacement therapy before a male-to-female athlete can compete.

Transgender boys and girl teens experience discrimination and attempt suicide more often that other teens. Being able to participate in sports in high school helps their feelings of self-worth. Including such teens in athletic competitions helps their feelings of self-worth. But what about the hundreds of high school girls who compete against them? What about their feelings? Stonington High School junior Kate Hall, who won the Class M 100 in 2016, cried after she finished second behind Yearwood in the same event in 2017.

According to *Mother Jones*, "Nearly 40 states have adopted policies for high school transgender athletes. Some allow students to play on teams based on gender identity, without any kind of hormone requirement, while others restrict them to teams matching the sex on their birth certificates. Nebraska's policy takes a middle road—and has fueled outrage on all sides. It also comes at a time of national debate over trans rights in schools. Twenty states sued the Obama administration over a letter sent to American public schools from its Department of Education, saying they could lose federal funding if they discriminated against transgender students, who should be allowed to play on sports teams matching their identity."

"Critics on the right worry the policy makes it *too* easy for trans kids to compete. 'As the father of two daughters, I would be very concerned about boys competing against my daughters in sports,' Republican Gov. Pete Ricketts said. The Nebraska Catholic bishops weighed in, too, noting that 'this would certainly have a negative impact on students' and society's attitudes towards the fundamental nature of the human person and the family.'"[4]

Questions:

1. Should Title IX, a law that prohibits sex discrimination in federally funded schools, also protect the rights of transgender students in athletic competitions?
2. Does allowing Andraya Yearwood to race against female athletes violate the rights of those athletes, or create an injustice of any kind?
3. In the vast majority of high school athletic competitions, males and females do not compete against each other. Is is possible to resolve the tension between reasons supporting this division and reasons for allowing transgender athletes to compete in the group with which they self-identify? If not, which reasons take precedence and why?

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[4] Smith, Cam. 2017. "Connecticut transgender sprinter Andraya Yearwood wins two state titles amidst controversy." USA Today. http://usatodayhss.com/2017/connecticut-transgender-sprinter-andraya-yearwood-wins-two-state-titles-amidst-controversy.

Mathew Conyers, "At Cromwell High, Transgender Athlete Competes with Girls for First Time," Hartford Courant, April 7, 2017. http://www.courant.com/sports/high-schools/hc-hs-cromwell-track-andraya-yearwood-0407-20170406-story.html

Jacobs, Jeff. 2017. "Jeff Jacobs: As We Rightfully Applaud Yearwood, We Must Acknowledge Many Questions Remain." Hartford Courant. http://www.courant.com/sports/hc-jacobs-column-yearwood-transgender-0531-20170530-column.html.

Michaels, Samantha. 2016. "High Schools Are the Next Battleground in the Fight Over Transgender Athletes." Mother Jones. http://www.motherjones.com/politics/2016/09/transgender-students-school-athletics-nebraska-title-ix/.

Andrews, Malika. 2017. "How Should High School Define Sexes for Transgender Athletes?" The New York Times. Last modified November 8. https://www.nytimes.com/2017/11/08/sports/transgender-athletes.html.

Case 3: An Undocumented Minor

Miguel arrives to the emergency department (ED) with multiple stab wounds. He is conscious and will not reveal how the injuries occurred. Miguel only speaks and understands Spanish. When asked, he says that he is 16 years old, but he will not give his birth date, address, or contact information. He has no insurance, medical records, or any documentation at all. The ED team addresses the wounds they see and stabilize him, and they admit him to the hospital for further monitoring.

His new medical team evaluates him, and they are concerned that whatever he was stabbed with could have nicked an organ. Although Miguel does not appear to have internal bleeding at the moment, he also refuses further tests. He insists repeatedly that he wants to leave the hospital, though he agrees to talk with a surgical resident who is fluent in Spanish. The resident explains to Miguel their concern about a punctured organ that could quickly become fatal. The resident clarifies that the team could find out whether the organs are intact through a relatively non-invasive procedure, an exploratory laparoscopy. Miguel states that he understands that he could die if his organs have been perforated, but he wants to leave anyway. When asked why, Miguel simply says, "I want to go because I want to go."

A social worker joins the conversation and asks the resident to convey to Miguel the hospital's moral and legal responsibility for safe discharge out of the hospital. Without any knowledge of Miguel's living situation or social support (like family who could bring him back to the hospital if needed), the social worker believes that they cannot ensure a safe discharge. In response to these questions, Miguel becomes increasingly agitated. The resident tells the social worker that he believes Miguel understands the risks, and the team should not coerce or force him into staying any longer. The social worker points out to the resident that Miguel is a minor, and she does not think he can sign an AMA form (acknowledging that he is leaving against medical advice) for himself. The resident tells Miguel this, and Miguel says that he is 17 years old and should be able to sign for himself, just like he signed a general consent when he was admitted from the ED.

At this time, a young man arrives, and Miguel says that this man is his adult cousin. The young man, Jose, stays near the door. The resident summarizes Miguel's situation for Jose, and Jose says he will not sign any paperwork for Miguel. The social worker asks Jose about Miguel's living situation, and Jose reveals that Miguel lives alone in an old building downtown. Jose indicates that Miguel does not rent or own the property. Worried that Miguel is squatting in an abandoned building, the social worker presses Jose to tell her where Miguel's family is. Jose whispers to her that Miguel's parents dropped him off in the United States "years ago," and Miguel has had no contact with them ever since. Miguel and Jose then begin to argue in rapid Spanish. Jose informs the resident that he advised Miguel to let the doctors do whatever they need to do, but Miguel still refuses. Jose leaves the hospital.

<u>Questions:</u>

1. Is it ethically permissible for Miguel to sign the AMA form for himself and leave the hospital without further tests or monitoring?
2. What are the limits of a hospital's ethical duty of safe discharge?
3. Given the ways in which Miguel has been rendered vulnerable as an undocumented minor, are there additional ethical responsibilities that the hospital or society have in protecting and caring for patients like Miguel?

Case 4: Itching to Tell

Renita is a 30 year-old female with severe psoriasis, a chronic disease in which the body's immune system causes skin cells to grow rapidly, producing itchy, red patches on the surface of the skin. Topical ointments seldom have an effect on the symptoms of Renita's psoriasis, so her dermatologist prescribed methotrexate, a drug that slows the growth of skin cells and suppresses the immune system. When she takes the drug, her symptoms fade very quickly, and she is very satisfied with the results.

Methotrexate, however, is a teratogenic drug—it can interfere with the development of an embryo or fetus, causing birth defects. The FDA's label for the drug states: "Methotrexate has been reported to cause fetal death and/or congenital anomalies. Therefore, it is not recommended for women of childbearing potential unless there is clear medical evidence that the benefits can be expected to outweigh the considered risks. Pregnant women with psoriasis or rheumatoid arthritis should not receive methotrexate."[5]

When her dermatologist prescribed methotrexate two years ago, Renita was not sexually active, and she agreed to continue to take birth control.

Renita has a talkative but depressive personality; during several appointments over the last two years, when her dermatologist would greet her with, "How are you doing?" Renita would express morose dissatisfaction about being unmarried and would detail her concerns about "no one wanting to marry her" due to her weight and health conditions, including her psoriasis. During the most recent appointment, however, Renita disclosed to her dermatologist that her methotrexate "works so well" and that she has become engaged. In addition, Renita described her plans to have children as soon as she gets married next month.

In response, Renita's dermatologist warned her that methotrexate can cause severe birth defects and requested that she discontinue using her remaining supply, which is enough for Renita to use throughout a significant portion of her pregnancy. In response, Renita revealed that her fiancé would "definitely want me not to take the drug anymore if he found out what it could do, or he wouldn't want to have any children with me. I can't have that. Plus, if we have a disabled child, he'll never know it's from the methotrexate." She stated that she would probably keep taking the drug despite its effects. "I don't think my fiancé would stay with me if he knew about the psoriasis, so I need to take it. If he doesn't marry me, I'll be lonely forever. I guess I'll take my chances. I'd rather have a disabled child and a husband I keep a secret from than no one at all."

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[5] FDA, Methotrexate tablet label, accessed Nov. 2017, URL: https://www.accessdata.fda.gov/drugsatfda_docs/label/2016/008085s066lbl.pdf

Her dermatologist asked, "What about your husband? Wouldn't he want to know? Wouldn't you want to know if you were in his shoes?" Renita didn't seem to care. Her dermatologist then suggested that her future child will not want her to have taken the methotrexate. But given recent findings about how having a disability might not be a bad thing for those who have a disability,[6] and given that there is currently not a child whose rights the dermatologist could appeal to, Renita's dermatologist dropped the point and considered what she should do.

Questions:

1. Does Renita's dermatologist have an ethical obligation to disclose to Renita's fiancé that she has been taking a drug that can cause birth defects? Why or why not? If her dermatologist has an obligation to disclose information to Renita's fiancé, how much information should she provide?
2. The court in the Tarasoff case ruled that physicians have an obligation to warn officials or potential victims of patients' potentially harmful actions. Is there a potential victim in this case, and if so, is it the husband, the child or both?
3. What should enter into physicians' considerations when determining when they have a duty to warn?

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[6] See, e.g., Elizabeth Barnes, The Minority Body, and Stephen Campbell and Joseph Stramondo, "The Complicated Relationship of Disability and Well-Being," Kennedy Institute of Ethics Journal 27:2, 151-184 (2017). URL: https://muse.jhu.edu/article/665104/pdf

Case 5: Whose Final Wishes?

Dee was a keenly intelligent, highly educated and professionally accomplished woman. A sister, wife, and mother of three, she was disciplined and proudly self-sufficient. Perhaps because her mother had had Parkinson's disease, Dee had long feared that she, too, might develop some sort of progressive and incurable disorder that would render her incapacitated and reliant on others. She knew she would not want to go on if she could not continue to live the good and productive life she had created for herself. She made certain, therefore, to tell her family that should she become profoundly intellectually or physically incapacitated, she did not want any medical intervention to save her life should it be threatened by illness or accident. Although she did not document her wishes in writing, her family understood clearly that beyond comfort measures, Dee wanted nothing that would prolong a life she was sure would hold little value for her.

As she had feared, in her fifties Dee developed dementia. Once enormously articulate, she lost her verbal powers. Once fastidious, she grew sloppy in her dress and her home was messy and dirty. Her memory began to fail and increasingly, she could not be safely left alone. She forgot how to use a key to unlock the door to her house. She did not remember to shut off the gas on the stove. Her worst fears had been realized, and yet to the surprise of her family, there were welcome changes in Dee. She was becoming a happier person. She seemed to enjoy her life. She became less demanding and her demeanor softened. When at last she had to be moved to a memory care center, she seemed not glum but cheerful. She high-fived the staff and danced with a male aide she liked. She quickly became the center of a social circle in the facility. She was no longer afraid; she was calm. Her family was sure that her life was enjoyable to Dee, that it was valuable for her, at least for now.

Yet Dee's life no longer contained most of the elements she had deemed so important earlier, and she had made her wishes about the end of her life plain. Her family, who once agreed with Dee's instructions, now wondered whether they should be honored. Should they really, on Dee's behalf, refuse all life-saving medical interventions, not just ventilation or artificial nutrition, but even a transfusion or antibiotics? Dee seemed to have become a different person from the sister, wife and mother who once had been so insistent that a life of disability was a life not worth living.[7]

Questions:

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[7] Inspired by https://www.statnews.com/2016/09/16/dementia-last-wishes/

1. Should Dee’s family request life-saving intervention if she has an accident or serious illness? Why or why not?
2. Should Dee’s family attempt to forge a new end-of-life plan for her based on the evidence about what she would want since she developed dementia?
3. If Dee were able to communicate nonverbally about life-saving medical interventions, are there good reasons for allowing Dee’s prior wishes to trump her wishes in a noncompetent state? Why or why not?

Case 6: Keeping Confidentiality

Sabir is a 40-year old lawyer who drives part-time for Uber as a hobby. Last week, Sabir had a grand mal seizure for the first time in his life. Since then, he has had an absence seizure (a seizure characterized by impairment of consciousness) and another grand mal seizure. His physician, Dr. B, diagnosed Sabir with epilepsy and started a regimen of anti-seizure medication. Knowing about Sabir's part-time work for Uber, Dr. B notified Sabir of the risks and dangers of driving with epilepsy and the potential harm to others, especially when starting anti-seizure medication, which has uncertain effects. Dr. B strongly advised Sabir to discontinue driving until he was seizure-free for at least three months.

Sabir, however, told Dr. B that he understood that Dr. B had to inform him of the risks; nevertheless, Sabir revealed that he would not stop driving for Uber. Even after Dr. B reiterated the dangers and potential loss of lives, Sabir dismissed the concerns as "overblown."

Most states, including New York, where Dr. B's clinic is located, do not legally obligate a physician to report patients' health conditions, even when those conditions pose a safety hazard. Instead, many states, such as New York, require drivers of commercial vehicles, like buses, to undergo a periodic medical examination.[8] The requirement to have a periodic medical exam, however, does not apply to those without a commercial driver's license, like Sabir and many other Uber drivers.

Although physicians do not have a legal obligation to report, the American Medical Association writes that physicians have a moral obligation to report unsafe drivers to the DMV even if laws do not require that they do so: "In those situations where clear evidence of substantial driving impairment implies a strong threat to patient and public safety, and where physicians' advice to discontinue driving privileges is disregarded, physicians have an ethical duty to notify the DMV of the medical conditions which would impair safe driving."[9]

Dr. B, recalling the AMA's statement, informs Sabir that, as a physician, he has a moral obligation to inform the DMV that Sabir has epilepsy. Sabir replies that it is "useless" to report to the New York DMV, because he has a Wyoming driver's license, and Wyoming probably does not have any restrictions on licenses due to seizures. The New York DMV can't do anything about that. (Later, after some research, Dr. B determines that Sabir is correct—unlike most states, Wyoming does not have a set

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[8] For a summary of New York's laws concerning commercial vehicle drivers with potentially harmful medical conditions and physicians' obligation to report in that state, see Berger et. al. for the Committee on Bioethical Issues of the Medical Society of the State of New York, "Reporting by Physicians of Impaired Drivers and Potentially Impaired Drivers," Journal of General Internal Medicine, 15(9): (2000), 667–672. URL: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1495589/

[9] Council on Ethical and Judicial Affairs, *Code of Medical Ethics: Current Opinions with Annotations*. Chicago, Ill: American Medical Association; 1997, 77. The decision was reaffirmed in 1999.

period during which a license-holder with a seizure must discontinue driving,[10] and New York's DMV would probably be powerless in this situation.)

Moving beyond the AMA's statement, Dr. B, remembering the Tarasoff case, cites the ruling to Sabir: physicians have a "duty to exercise reasonable care to protect the foreseeable victim[s] of the danger" when they perceive the patient's condition to pose a public threat. [11] The majority decision in the Tarasoff case notes that physicians may be called to "notify the police, or to take whatever other steps are reasonably necessary under the cirumstances…"[12]

Sabir strongly suggests that Dr. B not report his condition and replies that although he does not wish to resort to retaliatory measures, he could bring legal action against Dr. B for disclosing his confidential health information, and he would not hesitate to report Dr. B's violation of patient confidentiality on rateMD.com, which will certainly cause Dr. B to lose patients.

As Sabir leaves the clinic, Dr. B considers whether and, if so, how, to report Sabir's condition.

<u>Questions:</u>

1. Does Dr. B have a duty to warn? If so, how should Dr. B do so and whom should he contact?
2. WebMD and other public rating sites present a conflict of interest to physicians that they cannot avoid; patients are able to give physicians a lower rating unless the physician complies with their demands. Should Sabir's WebMD threat influence Dr. B's decision about whether to warn? If so, how should it influence the decision?
3. Technology such as Uber and WebMD present new ethical challenges for physicians by working around traditional infrastructures. How should the sudden rise in these kinds of business models influence the decision-making of physicians, if at all?

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[10] Epilepsy Foundation, State Driving Laws Database, accessed Nov. 2017. URL: https://www.epilepsy.com/driving-laws/2008891

[11] Justice Matthew O. Tobriner (Majority Opinion). California Supreme Court, Tarasoff v. Regents of the University of California, 131 California Reporter 14 (July 1, 1976).

[12] Ibid.

Case 7: Who's Your Momma?

Melissa Cook was a 47-year-old California surrogate who made news in 2015 when she went public with her feud with Chester Moore Jr, the biological father who paid her $33,000.00 to have a child by in vitro fertilization (Dodd). Before becoming pregnant, in signing the surrogacy agreement, Cook agreed to selective reduction of multiple embryos if necessary for medical reasons. Doctors created and transferred to Cook three embryos using Moore's sperm and donor eggs from a 20-year-old woman. Doctors told Moore that a multi-fetal pregnancy and birth would be risky, so he requested that Cook selectively reduce upon the physicians' recommendation (Vaughn). But according to Cook, after the three embryos proved to be viable, Moore allegedly first demanded Cook abort all, then later one of them because he claimed he could not afford to raise them. Cook refused to abort, claiming "I am pro-life and I'm not having an abortion" (Cleveland).

Cook was concerned about Moore's fitness to parent, based on this incident and the fact that he is a deaf, mute, single postal worker. She filed a lawsuit to challenge the constitutionality of California's surrogacy law, which treats the intending parents as the only legal parents of surrogate-born children, and which terminates before birth the surrogate's parental rights to the children that result. Her suit was rejected by the court.

Cook went into labor two months early, and the premature triplets were placed in a neonatal intensive care unit for three months. Despite her repeated requests, she was not permitted to visit the babies and was not allowed to receive any information about their condition because she had no legal rights over them. Moore, who lives in Georgia, is reported to have only visited briefly with the babies during their hospitalization. The triplets were eventually discharged and sent home to Georgia with Moore, since he was recognized by California surrogacy laws as the legal parent.

In July 2017, Cook appealed her case with the U.S. Supreme Court where she claimed that the California surrogacy laws violate the federal equal protection clause. According to the appeal, "Cook asked the justices to decide six constitutional questions, including whether California's Gestational Surrogacy Statute violates the equal protection or substantive and procedural due process rights of either surrogates or babies born to surrogates" (Cleveland). The Supreme Court ultimately refused to hear the appeal.

Legal and medical experts claim that Cook's case is anomalous, and that most commercial surrogacy cases proceed smoothly without any such difficulties.

As Kathleen Sloan, co-author of an amicus curiae ("friend of the court") brief filed in support of Cook, argued: "Surrogacy is creating a generation of children severed from biological and genetic identity and a breeder class of marginalized women. Both are being transformed into commodities for sale on the global marketplace. This can only be accepted and condoned by a society untethered from any sense of ethics, human rights, dignity, or moral values. When the primal bond—as ancient as humankind itself—between mother and child is destroyed, what will be left?"[13]

Questions:

1. Are California's surrogacy laws morally permissible as they stand? Morally optimal? Why or why not?
2. What difference should anomalous cases like this make to commercial surrogacy laws in California?
3. Who has the moral right to raise the children who result, if anyone does? Why?

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[13] Margot Cleveland, "Supreme Court Refuses Surrogacy Case Of Mother Pressured To Abort Triplet," http://thefederalist.com/2017/10/03/supreme-court-refuses-hear-surrogacy-case-mother-pressured-abort-extra-triplet/
Johnny Dodd, "Surrogate Mom Melissa Cook Reacts to 'Horrifying' Allegations About Birth Father of Her Triplets: 'They're Helpless'," http://people.com/human-interest/surrogate-mom-melissa-cook-horrifying-allegations-birth-father/
Rich Vaughn, "California Court Rules Surrogacy Is Constitutional," https://globalivf.com/2017/02/01/california-court-rules-surrogacy-is-constitutional/

Case 8: Balanced Diet

In Haiti's capital, Port-Au-Prince, new mothers who are HIV positive are under pressure to comply with the recommended health guidelines for infant nutrition, which emphasize the importance of breastfeeding for at least 6 months. Many of these mothers live with food-insecurity (reduced quality, variety, desirability of diet; disrupted eating patters; reduced food intake). In addition, many of these mothers report receiving conflicting instructions regarding infant feeding: while they heard the WHO message that they should exclusively breastfeed until 6 months, they also felt pressure to conform to the widely accepted cultural norm of feeding the child other food if it was showing signs of hunger after breastfeeding.[14]

The World Health Organization's 2016 guidelines state that "exclusive breastfeeding for the first six months of life is the recommended way of feeding infants, followed by continued breastfeeding with appropriate complementary foods for up to two years or beyond."[15] For mothers who are HIV positive, the WHO recommends antiretrovirals to stop the vertical transmission of HIV through breastfeeding, and also suggest that as long as there is no evidence of clinical, immune, or viral failure, mothers should breastfeed for at least 12 months. Moreover, it says, "for women living in food-insecure regions, continuing breastfeeding beyond 12 months may still be important for the child to achieve an adequate diet."

When it comes to maternal health of mothers living with HIV in Port-Au-Prince, most of the advice is focused on doing what it takes for the infants to be breastfed in the early months; for instance, "Eat well if you are breastfeeding so that your milk has strength," "Eat everything you find so that you can continue breastfeeding," and "Take your medication correctly for the baby not to get sick." Because of the widely accepted cultural assumption that women have a duty to breastfeed and these messages from healthcare workers, mothers living with HIV who already shoulder the burden of managing their disease and mothers who experience food insecurity may feel shame in the healthcare environment when their infants are not able to exclusively breastfeed.

<u>Questions:</u>

1. Is it appropriate for healthcare professionals to treat infant nutrition as top priority in places where there are scarce resources?

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[14] Fox EL, Pelto GH, Rasmussen KM, et al. Who knows what: An exploration of the infant feeding message environment and intracultural differences in Port-au-Prince, Haiti. Matern Child Nutr. 2017;. https://doi-org.libproxy.usouthal.edu/10.1111/mcn.12537

[15] "Updates on HIV and Infant Feeding," World Health Organization, 2016: 1-68. http://www.who.int/maternal_child_adolescent/documents/hiv-infant-feeding-2016/en/

2. Should healthcare teams in Port Au Prince try to effect compliance with the WHO recommendations for infant nutrition among mothers living with HIV even if the recommendations negatively affect them?
3. How should the healthcare team approach infant nutrition for mothers living with HIV who do not have access to antiretrovirals?

Case 9: Pediatric Bariatric Surgery

Aliayha Carrasco-Garcia, age 15 and weighing 240 pounds at 5-foot-2, planned to undergo bariatric surgery in 2017. Previously, she had failed to lose weight through exercise and dieting.

Aliayha represents an ominous trend in America, where the number of teens with a BMI over 30 has jumped from 5% of American teens in 1999 to 10% in 2014.[16] Worldwide, teenage obesity is increasing and medicine increasingly fights it everywhere.[17] Instead of surgery food to curb teenage obesity, some professors of public health urge taxes on sodas and junk.[18]

Should surgeons proceed with surgery on Aliayah? Does it send the wrong message that teenagers can gain a hundred pounds of excess weight and then surgeons can normalize them? Should an overburdened medical system pay for such surgery? For those on Medicaid?

"Bariatric surgery" is a phrase that covers all uses of surgery to improve the health of overweight patients. Bariatric surgery is usually reimbursed by medical plans for patients with a body mass index (BMI) over 40. The BMI is considered a better measure of extreme obesity than a patient's numerical weight.

The phrase "morbid obesity" usually triggers reimbursement for surgery. Morbid obesity can interfere with basic physical functions, significantly increases the risk of obesity-related diseases such as stroke and type-2 diabetes.

The two dominant surgeries of bariatric surgery are the gastric bypass and the gastric sleeve. Both surgeries permanently reduce the size of the stomach. In gastric bypass procedures, surgeons divide the stomach into a small, upper pouch and a larger, lower catch-pouch for remnants. Afterwards, they connect the small intestines to both.

Some studies of the long-term effects of bariatric surgery show that patients liked it and some adults wish they had done it sooner. Bariatric surgery improves blood sugar, blood pressure, lipid levels, sleep apnea, and reduces risk of cardiac arrests. In a study of 2500 veterans, those who had undergone bariatric surgery had lower death

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[16] Gina Kolata, "One Last Chance," *New York Times*, Feb. 28, 2017, D1.

[17] Edward Gregg and Jonathan Shaw, "Global Health Effects of Overweight and Obesity," *New England Journal of Medicine 377;1;* July 6, 2017, 8081.

[18] David Buchanan, "Ethical Considerations in Public Health Policies to Reduce the Health Consequences of Obesity," *Lahey Health Journal of Medical Ethics*, Fall, 2016, p. 4.

rates 14 years later than controls.[19] Other studies claimed gastric-bypass patients reduced long-term, early mortality by 40 percent.[20]

Many objections exist to the use of bariatric surgery in teenagers, some value-laden. Many people consider such surgery for excess weight to be frivolous and extreme, a last-resort for weak-willed people and a financial drain on the medical system.[21] Critics argue that age 15 is way too young to experience such radical surgery and that therapy, exercise and dieting must be tried over a decade before fat kids undergo the surgeon's knife. Such surgery also seems like a luxury for the overweight rich, a quick-fix that doesn't hold up over the long-run, and (like any surgery and anesthesia) a dangerous procedure not to be undertaken lightly.

Insurers understandably resist paying for surgery for a new class of teenage patients. Although they approve most requests in adults with BMI over 40 for bariatric surgery, they deny such requests for bariatric surgery in teenagers with the same BMI. Is this consistent. Carrasco-Garcia's surgeons will need to ask her insurer many times and even plead to get her surgery approved.

Some studies suggest that the earlier that teenagers have the surgery, the better the results. Even when approved, insurers require a high BMI of teenagers eligible for this surgery: those without blatant medical conditions need a BMI of 50, and with such conditions, a BMI of 40.[22]

Finally, after gastric bypass surgery, more things need to be done. First, more surgery will be needed to reduce excess skin. Paul Mason, the subject of a series on TLC about him, once weighed 980 pounds and lost 650 pounds, but then carried many pounds of excess skin (in one surgery alone, surgeons removed 50 pounds of skin from his abdomen).[23] Mason first felt trapped in his nearly one thousand pounds but after losing 650 pounds, still felt trapped in his excess skin. Second, counseling with nutritionists and psychologists will be need so that the teenager does not gain the weight back quickly. Unless surgery is followed with these activities, it might well need to be done again a decade later.

<u>Questions:</u>

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[19] Arterburn DE et al. "Association between Bariatric Surgery and Long-term Survival," *JAMA*. 2015 Jan 6;313(1):62-70; Arterburn D, Livingston E, Olsen M, et al." *Obesity Research and Clinical Practice* September 2013;7(5): 367-e376.

[20] Adams TD, Gress RE, Smith SC, et al. (August 2007), "Long-term mortality after gastric bypass surgery," New England Journal of Medicine 357 (8): 753–61; Sjöström L, Narbro K, Sjöström CD, et al. (August 2007), "Effects of bariatric surgery on mortality in Swedish obese subjects," New England Journal of Medicine 357 (8): 741–52.

[22] Gina Kolata, "One Last Chance," p. D3.

[23] Sarah Lyall, "Hundreds of Pounds Later, Still Shedding Burdens," *New York Times*, September 3, 2016, p. A17

1. Should bariatric surgery be permitted for teenagers? If so, under what conditions? If not, why not?
2. If Aliayah receives surgery, should it be classified as elective? Should bariatric surgery for someone in Aliayah's position be covered by insurance and Medicaid?
3. What are the ethical implications of the message sent by allowing Aliayah to undergo bariatric surgery at her age? What are the ethical implications of the message sent by disallowing her to do so?

Case 10: **Miss V**

Generally, parents are given a wide degree of latitude in making decisions in the best interests of their children, since they tend to know their children and their children's needs better than anyone else. But in October 2017 the British high court ruled that a 21-year-old woman with severe cognitive disability must be fitted with a contraceptive patch against the wishes of her mother.

Miss V, the subject of concern, has a severe mental disability that resulted from an accident when she was 3 years old. She has the permanent mental capacity of a 5-year-old child. Her mother, referred to in court as Mrs. W, rejected the contraception plan, claiming that increased protective measures for Miss V would suffice.

Miss V's case became known to the court after she gave birth to a baby boy in 2016, at which point the boy was immediately placed in foster care. Her suspected rape by a family friend was not detected until Miss V was discovered to be 28 weeks pregnant during a routine doctor's appointment. Mr. Justice Cobb noted that "Miss V was wholly bewildered by the experiences of pregnancy and confinement, and immensely distressed when her baby was removed from her care, pursuant to emergency orders"(Hill, 2017). The state believed that, based on past failures to uphold Miss V's safeguarding plan, her lack of capacity to consent, and the severe negative emotional and psychological harm that was caused by her pregnancy and birth experience, it would be in Miss V's best interests to be placed on long-lasting contraception. The patch was determined to be the least invasive and least harmful method of protecting her interests.

The family's legal counsel raised the following objections to requiring Miss V's use of the contraceptive patch: (1) even this least restrictive form of contraception has side effects which are likely to outweigh the potential benefits; (2) Miss V's safeguarding plan would not be any tighter or more detailed if contraception is not administered, which demonstrates that the mandated contraception adds little to the protections offered; and (3) administering the patch subjects Miss V to greater risk of sexual exploitation, since the sexual predator might know that she has contraceptive protection, and any sexual abuse would likely go undetected (since her previous rape was only discovered because of the pregnancy) ([2017] EWCOP 20)

But the court pointed out that Mrs. W's own health problems render her unfit to safeguard Miss V against future sexual assault and pregnancy. In fact, it was while Mrs. W was hospitalized overnight with an acute illness that Miss V was sexually assaulted and became pregnant. As Justice Cobb claimed "I find that there is a real chance that Mrs W's focus on her daughter's safety and wellbeing has been, and may yet be, unavoidably diverted by her own health needs or dramas….She told me that she has a lot of physical health problems, that she takes 13 tablets a day, including antidepressants."(Hill, 2017).

The contraceptive patch is to be worn by Miss V for a six month trial period, at which point its use will be reassessed. If there are "painful or uncomfortable side effects, then the patch could be withdrawn and the matter restored to court" ([2017] EWCOP 20).[24]

Questions:

1. Is it morally permissible for a judge, like Justice Cobb, to mandate a contraceptive patch for Miss V? Why or why not?
2. Could state-mandated birth control be morally permissible in a case where the patient is not competent and existing children will be affected by the introduction of another sibling? Why or why not?
3. Who, if anyone, has the moral standing to make a decision about Miss V's fertility? Why?

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[24] Hill, Amelia, "Woman with severe learning disability to get contraceptive patch against mother's wishes," *The Guardian*, October 27, 2017. https://www.theguardian.com/law/2017/oct/27/woman-with-severe-learning-disability-to-get-contraceptive-patch-against-mothers-wishes

Stowe Family Law LLP, "Woman with learning difficulties to be given contraceptive patch," October 26, 2017. http://www.marilynstowe.co.uk/2017/10/26/women-with-learning-difficulties-to-be-given-contraceptive-patch/

http://www.bailii.org/ew/cases/EWCOP/2017/20.html (The Hospital Trust vs. V and Others)

Case 11: Amputees and Different Societies

Quentin and Dominique live in an isolated community where most members of the community are born with a genetic medical condition that requires partial amputation of both legs at some point during early childhood. Both Quentin and Dominique have had their legs partially amputated and rely on the use of prosthetics. In this society, prosthetic limbs are easily available and widely varied. Everyone with amputated limbs has several pair. People select prosthetics that enable them to adjust their height on a whim, jump higher, run faster, swim and dive with greater ease, perform impressive acrobatic tricks, express their fashion sense and individuality, and so on.

Quentin and Dominique are trying to conceive but have experienced fertility issues. As a result, they have opted for a specialized IVF (in-vitro fertilization) procedure. At the beginning of this procedure, the doctor accesses the genetic make-up of selected sperm and eggs in order to determine the genetic make-up of the embryo she will ultimately implant. After assessing the gametes for the healthiest possible combinations, the doctor tells the couple that there are two options. First, she can fertilize an egg and transfer an embryo into Dominique's uterus that will grow into a child who will not suffer from the genetic medical condition that will eventually require amputation and prostheses. Second, she can fertilize a different egg and transfer a different embryo into Dominique's uterus that will grow into a child who will ultimately require partial amputation of both legs due to the common genetic condition in this society. Aside from this difference, the two potential embryos would be identically healthy.

Quentin and Dominique are worried about the social costs of having a child who will not need prosthetic limbs and who will thereby not be able to participate fully in many community social activities. They also wish to have a child who can share in the lifestyle they enjoy—a lifestyle that involves the use of prosthetic limbs. The opt to have a child with a genetic medical condition that will result in amputation, and 9 months later they give birth to Tamara. Tamara has her legs partially amputated at age 6, at which point she receives her first pair of prosthetic limbs.

Diego and Maya live in a community where most members of the community are born with fully functioning limbs. Both Diego and Maya have a genetic medical condition that required them to have their legs partially amputated at an early age. They both rely on the use of prosthetics. Prostheses are not common in this society, though some members rely on them. They can be expensive to obtain, and those who require them often have only one affordable prosthetic option. Diego and Maya are trying to conceive but have experienced fertility issues. As a result, they have opted for a specialized IVF procedure. At the beginning of this procedure, the doctor accesses the genetic make-up of selected sperm and eggs in order to determine the genetic make-up of the embryo she will ultimately implant. After assessing the gametes for the healthiest possible combinations, the doctor gives the couple the same options as were available to Quentin and Dominique.

Diego and Maya are worried about the social costs of having a child who will need prosthetic limbs and who will thereby not be able to participate fully in many common social activities. They also wish to have a child who can share in the lifestyle they enjoy—a lifestyle that involves the use of prosthetic limbs. They opt to have a child with a genetic medical condition that will result in amputation, and 9 months later they give birth to Ana. Ana has her legs partially amputated at age 6, at which point she receives her first pair of prosthetic limbs.

Questions:

1. Should Tamara be considered disabled/ability-impaired? Should Ana? What should determine whether these individuals qualify as disabled/ability-impaired?
2. Neither Tamara nor Ana would exist had their parents opted for the other sperm-egg combination. Did Quentin and Dominique harm their child through their reproductive choices? Did Diego and Maya?
3. Did Quentin and Dominique have an ethical obligation to produce a child with a certain genetic make-up? Did Diego and Maya? If so, why? If not, why not?

Case 12: A Question of Fidelity

Mr. John Burke is a 54-year-old married man, the father of three daughters, a professor of marketing, and a patient of Dr. Robert McMahon now for the past four years. He comes to the office today for his annual physical. His exam confirms what Dr. McMahon suspected upon Mr. Burke's presentation; namely, that Mr. Burke is a healthy man.

"Everything looks good, Jack," concludes Dr. McMahon, with a pat on the back as Mr. Burke rights himself on the exam table. "You've even lost four pounds since I saw you last. You're doing great." Reaching for his pad to write a prescription for a persistent allergy, he adds with characteristic warmth, "I wish more of my patients were like you."

Mr. Burke smiles, slides his arm into the sleeve of his shirt and begins buttoning, reluctant to interrupt the physician's pen on pad with his question. "Glad to hear it, Doc. I — there is — uh — there's one more thing I want to talk to you about."

Dr. McMahon leans against the exam room counter, rests his hands in his pockets and faces Jack, offering his full attention. "Of course, Jack. What's on your mind?" "I'm having some problems with impotence — you know, ED, erectile dysfunction."

In response to Dr. McMahon, saying, "Oh, I'm so sorry to hear that. It must be putting a strain on your marriage," Mr. Burke replies, "Oh no, Doc. Angela and I have not been intimate with each other in over a year. I'm having this problem with the woman I'm having an affair with. She's much younger than me, and it's really embarrassing."

"Oh, okay. Fill me in a little bit." Less than a minute into Mr. Burke's recounting of his experiences in the past month, Dr. McMahon mercifully relieves him of his narrative, saying, "Jack, this certainly sounds like what you think it is, and it's not at all uncommon. Know that there is nothing more serious going on here. You're healthy and have nothing to worry about. And as you probably already know, there are some options for medications out there that treat ED very successfully."

"Well, great. I mean, good then. I'm happy to hear that it's nothing serious. This isn't the easiest thing to talk about." "Please don't be embarrassed, Jack. I appreciate your trust and candor." "So which one of these medications would you recommend," asks Mr. Burke.

A pause precedes Dr. McMahon's answer as he takes a seat on his stool. "Jack, this is awkward for me, but I can't prescribe any of these medications for you." "What do you mean? Am I not a good candidate for these drugs?" "No, you certainly are. You're just the kind of person these pharmaceutical companies would want to reach," replies Dr. McMahon. "The problem is that I'm not the right doctor for you on this.

What I mean is that, as a point of principle, I don't prescribe these drugs for men outside of a marriage. I don't mean to put you in an uncomfortable position here, Jack. And again, I really appreciate your willingness to talk to me about this. It's just something that I feel committed to in my pract—" "Are you serious Doc? I mean, are you able to refuse this? But you're my doctor!"

Questions:

1. Has the doctor violated the physician-patient relationship?
2. Does the doctor have a claim to conscientious objection in this case?
3. What is the doctor’s professional obligation in this case? Personal obligation? Is there a difference?

Case 13: The Heart of Addiction

Christopher Miller is a 37-year-old male who has suffered from three bouts of endocarditis. At age 35, he received a pacemaker and valve replacement to treat his endocarditis.

Miller's physician, Dr. E, believes that Miller's repeated heart problems can be traced back to his opioid abuse that began in his 20s. When Miller was in college, he sustained a shoulder injury and underwent surgery. He was prescribed Oxycontin for post-operative pain but quickly began abusing his medications. Years later, he moved on to heroin and Suboxone, reusing needles for as long as a week, sometimes longer.

After the third time he got endocarditis, Miller decided to quit abusing opioids. He picked up a smoking habit at that time. Miller had to have a valve replacement shortly after his third bout with endocarditis.

Dr. E sees many patients like Miller, and has begun to track their health and the cost they impose on his hospital. Many of his patients continue to use drugs and do not inject these drugs with clean needles, ending up back in the hospital shortly after release for new heart problems. Dr. E estimates that the cost of treating a patient like Miller is about half a million dollars.

Meanwhile, Dr. E is trying to treat patients with heart trouble and no past history of substance abuse. Many of his patients have poor insurance with high deductibles; he routinely has to tell these patients that they will need to pay what they take multiple months to earn in order to meet the deductible on the surgery or device they need. Dr. E wonders whether he should even take any more patients like Miller. [25]

Questions:

1. Is it permissible for Dr. E to stop accepting patients whom he has evidence have abused opioids?
2. What resources should Dr. E give patients like Miller? Should Miller be eligible for a second valve replacement surgery if it is needed?

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[25] Rodolico, Jack. "Doctors Consider Ethics Of Costly Heart Surgery For People Addicted To Opioids," March 21, 2017. http://www.npr.org/sections/health-shots/2017/03/21/520830183/doctors-consider-ethics-of-costly-heart-surgery-for-people-addicted-to-opioids

3. Should hospital administrators make policies that prohibit certain patients from receiving expensive resources to allow them to distribute more resources to other patients?

Case 14: Pacemaker Reutilization in LMICs

Cardiovascular disease (CVD) is the leading cause of death worldwide. The vast majority of CVD deaths occur in low and middle-income countries (LMICs) where the cost of lifesaving pacemakers ($15,000-$50,000) is out of many peoples' reach. It is estimated that lack of access to pacemakers is responsible for 1 to 2 million deaths each year.

One possible solution to this problem is to provide used pacemakers from the deceased for re-implantation in patients living in LMICs. In surveys of morticians in the Midwest, 85% of deceased patients who possess a cardiac device were buried with their device, and most of the devices that were explanted before burial were discarded. With proper sterilization, many of these devices could be refurbished and reused to the benefit of patients in LMICs who cannot otherwise afford pacemakers. Proponents of this solution argue that it is a violation of the principle of beneficence to fail to provide refurbished pacemakers—which would help manage the pain, suffering, and risk associated with CVD—to those suffering from CVD in LMICs. They also argue that failing to distribute reusable pacemakers violates the principle of justice. Without reuse, they argue, those in LMICs will not have access to such devices at all, and they will continue to inequitably suffer from the consequences of CVD.

One problem with this solution, however, is that it operates at a lower standard of care for people in LMICs than in wealthier countries. It seems unfair (and possibly exploitative) to provide less than the best treatment to poorer populations when wealthier populations have access to best care. Moreover, the populations in question are vulnerable since they do not have alternatives. Arguably, therefore, they are not in a position to consent freely to receiving a substandard product—all reused pacemakers will have decreased battery life—or to the additional risks using refurbished devices may pose, including increased risk of malfunction and infection.

Although a meta-analysis including 18 cohort studies of pacemaker reuse showed that the risk of infection was not statistically different from the infection risk associated with implantation of new devices, standardized sterilization procedures for pacemakers have not been established. The same meta-analysis showed an increased risk of device malfunction for reused devices; 0.68% of re-implanted devices malfunctioned. In addition, reusing pacemakers makes it impossible to return the devices to the manufacturers once a user has died, a traditional practice that allows for analysis and continued quality improvement.[26]

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[26] Badin, Auroa, et al. "Pacemaker reutilization for those in underserved nations: examining preliminary data and future prospects." *Interventional Cardiology* 5.6 (2013): 695-702.
Ochasi, Aloysius, and Peter Clark. "Reuse of pacemakers in Ghana and Nigeria: medical, legal, cultural and ethical perspectives." *Developing world bioethics* 15.3 (2015): 125-133.

Questions:

1. Is it permissible to reuse pacemakers in LMICs?
2. Under what conditions, if any, is it appropriate or acceptable to provide different standards of care for different groups of people?
3. Do patients who use pacemakers or their families have an ethical obligation to request that pacemakers are explanted and reused if possible?

Case 15: Alternative Eating

For most Americans, 99% of our food comes from what might be called "the industrial food system." This system that allows all of us in the US to eat while only 2 million or so actually work on farms raising the plants and animals that go into food.

The system's externalities, however, have become increasingly prominent and visible over the past 10-15 years. They include: (1) heavy use of pesticides which have an adverse effect on key insects (such as bees), water supplies, and farmworkers; (2) monocropping and heavy till practices which leave the soil damaged, which then requires (3) the overuse of synthetic fertilizers, often petroleum based, which runoff into waterways; (4) confined and intensive animal agriculture, with its use of antibiotics and ammonia-laden waste; (5) massive petroleum consumption and attendant emissions required to produce and then transport from industrial farms to processing plants to markets.

Suppose that Susan learns about some of these externalities to the industrial system and is trying figure out how to eat ethically. She is tempted to take the advice of people like Alice Waters and Michael Pollan and go organic and GMO-free, buy her food from farmers' markets, and only purchase the products of "humanely treated" animals.

But she has also learned that this alternative food system has its problems. For one thing, it is much more expensive and less efficient. Susan can afford it, being a well-paid lawyer, but her lower income neighbors never could and will have to keep patronizing the local Shop n' Save. Moreover, it's scientifically certain that these alternative methods could not be scaled in such a way as to feed all 7 billion of us, much less the 9 billion+ expected to be alive in 2040. So there's a sense in which Susan believes she can't advocate that everyone else do what she does.

Finally, she reads some literature on "Life Cycle Analyses" that provide complete data about an item from origin to table. She becomes aware that her local food almost always produces more emissions per calorie than industrial food. Even if a banana is flown in on a massive jet from Ecuador, it turns out, it's going to cost less in terms of both dollars and emissions to do that than it would to produce all of our fruit locally, individually drive back and forth to the farms and farmers' markets.

<u>Questions:</u>

1. Should Susan adopt the alternative of eating only organic, GMO-free, humane, farmers' market foods? Why or why not?
2. What state or federal policies might help Susan to make more ethical choices about her eating?
3. In Susan's case, is it permissible to act in a way she would not advocate that everyone else act? Why or why not?