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Case Authors:

Sydney Green
Adam Hamilton, M.A.
Aline Kalbian, Ph.D.
Sara Kolmes
Will Livingston, M.T.S.
Tracie Mahaffey, Ph.D.
David McNaughton, B.Phil.
Michael Nair-Collins, Ph.D.
James G. Quigley, M.A.
Sam Sims, M.A.
Roberto Sirvent, Ph.D., J.D.
Bradford Stockdale, M.A.

Note: This packet contains fifteen cases, with three questions following each case. At the NUBC 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. Only twelve cases will be used in the competition.

CASE 1

Forced Caesarean Sections: Pemberton v. Tallahassee Memorial Regional Medical Center

On January 13, 1996, after more than a full day of labor, Laura Pemberton came to Tallahassee Memorial Regional Medical Center (now known as Tallahassee Memorial Hospital or TMH) seeking an intravenous infusion of fluids after becoming dehydrated. Ms. Pemberton had made the deliberate decision to deliver her baby at home with the aid of a midwife without any physician attending or standing by and without any backup arrangement with a hospital. This decision to deliver at home resulted from her inability to find a local physician who would allow her to deliver vaginally. All the physicians she contacted were concerned that a 1995 Caesarean section, which had left a vertical incision that extended up into the thickened myometrium (well beyond a traditional low vertical incision), presented a greater risk of uterine rupture during any subsequent vaginal delivery.

When she arrived at the hospital, Ms. Pemberton first saw a family practice resident on call for obstetrics, who brought the case to the attention of Dr. Wendy Thompson, a board-certified family practice physician whose practice included obstetrics. Dr. Thompson advised Ms. Pemberton that she needed a Caesarean section. Ms. Pemberton refused, saying she wanted only an IV so she could return home to deliver vaginally. Dr. Thompson declined to assist in that plan and instead notified hospital officials of the situation. Hospital officials set about securing additional opinions from board certified obstetricians Dr. A.J. Brickler and Dr. David R. O'Bryan, the chairman of the hospital's obstetrics staff. Dr. Brickler and Dr. O'Bryan each determined that a Caesarean was medically necessary. Meanwhile, the Pembertons left the hospital against medical advice, apparently surreptitiously.

The hospital set in motion a procedure devised several years earlier (and used once previously) to deal with patients who refuse to consent to medically necessary treatment. The hospital's attorney, John D. Buchanan, resolved to file a petition on behalf of the State of Florida seeking a court order requiring Ms. Pemberton to submit to a Caesarean section. Mr. Buchanan contacted Second Circuit Chief Judge Phillip J. Padovano to inform him of the situation and requested a hearing.

Judge Padovano convened an emergency hearing in the hospital. In response to the judge's questions, Drs. Thompson, Brickler and O'Bryan testified unequivocally that vaginal birth would pose a substantial risk of uterine rupture and subsequent death of the baby. Judge Padovano ordered Ms. Pemberton returned to the hospital. An attorney and a law enforcement officer went to Ms. Pemberton's home and advised her she had been ordered to return to the hospital. She was returned to the hospital by ambulance against her will.

Judge Padovano then continued the hearing in Ms. Pemberton's room at the hospital. Both she and Mr. Pemberton were allowed to express their views. The judge ordered that a Caesarean section be performed. A Caesarean section was performed, resulting in delivery of a healthy baby boy. Ms. Pemberton suffered no complications.

Ms. Pemberton filed a lawsuit against the hospital claiming that the forced Caesarean violated her substantive constitutional rights and that the legal procedures leading to entry of the order violated her right to procedural due process. Her lawsuit was dismissed.

Questions:

1. By arriving at the hospital in search of medical assistance (IV fluids), did Ms. Pemberton give up her right to choose how she wanted to deliver her baby?

2. Was the state justified in forcing Ms. Pemberton back to the hospital for a forced C-section?

3. Does a woman have the right to choose a course of action that might be harmful to her fetus?

References:

Laura L. PEMBERTON, et al., Plaintiffs, v. TALLAHASSEE MEMORIAL REGIONAL MEDICAL CENTER, INC., Defendant. United States District Court, N.D. Florida, Tallahassee Division. October 13, 1999.

CASE 2
"Death with Dignity": The Case of Brittany Maynard

Brittany Maynard was diagnosed on January 1, 2014, with grade 2 astrocytoma, a form of brain cancer, and had a partial craniotomy and a partial resection of her temporal lobe. The cancer returned in April 2014, and her diagnosis was then elevated to grade 4 astrocytoma, also known as glioblastoma, with a prognosis of six months to live. She moved from California to Oregon to take advantage of Oregon's Death with Dignity Law, saying she had decided that "death with dignity was the best option for me and my family." The main provisions of that law are as follows.

Under the law, a competent adult Oregon resident who has been diagnosed, by a physician, with a terminal illness that will kill the patient within six months may request in writing, from his or her physician, a prescription for a lethal dose of medication for the purpose of ending the patient's life. Exercise of the option under this law is voluntary and the patient must initiate the request. Any physician, pharmacist or healthcare provider who has moral objections may refuse to participate. The request must be confirmed by two witnesses, at least one of whom is not related to the patient, is not entitled to any portion of the patient's estate, is not the patient's physician, and is not employed by a health care facility caring for the patient. After the request is made, another physician must examine the patient's medical records and confirm the diagnosis. The patient must be determined to be free of a mental condition impairing judgment. If the request is authorized, the patient must wait at least fifteen days and make a second oral request before the prescription may be written. The patient has a right to rescind the request at any time. Should either physician have concerns about the patient's ability to make an informed decision, or feel the patient's request may be motivated by depression or coercion, the patient must be referred for a psychological evaluation.

The law protects doctors from liability for providing a lethal prescription for a terminally ill, competent adult in compliance with the statute's restrictions. Participation by physicians, pharmacists, and health care providers is voluntary

On October 29, 2014, she stated that "it doesn't seem like the right time right now" but that she would still end her own life at some future point. Maynard ended her life on November 1, 2014, with drugs prescribed by her doctor. She was survived by her mother, stepfather, and husband, all of whom were with her when she died. Maynard wrote in her final Facebook post: "Goodbye to all my dear friends and family that I love. Today is the day I have chosen to pass away with dignity in the face of my terminal illness, this terrible brain cancer that has taken so much from me ... but would have taken so much more.

She partnered with Compassion and Choices to create the Brittany Maynard Fund, which seeks to legalize aid in dying in states where it is now illegal. She also wrote a piece for CNN titled "My Right to Death with Dignity at 29". In that interview she wrote, in part, as follows:

> I considered passing away in hospice care at my San Francisco Bay-area home. But even with palliative medication, I could develop potentially morphine-resistant pain and suffer personality changes and verbal, cognitive and motor loss of virtually any kind. Because the rest of my body is young and healthy, I am likely to physically hang on for a long time even though cancer is eating my mind. I probably would have suffered in hospice care for weeks or even months. And my family would have had to watch that. I did not want this nightmare scenario for my family, so I started researching death with dignity. It is an end-of-life option for mentally competent, terminally ill patients with a prognosis of six months or less to live. It would enable me to use the medical practice of aid in dying: I could request and receive a prescription from a physician for medication that I could self-ingest to end my dying process if it becomes unbearable. I quickly decided that death with dignity was the best option for me and my family. I've had the medication for weeks. I am not suicidal. If I were, I would have consumed that medication long ago. I do not want to die. But I am dying. And I want to die on my own terms. I would not tell anyone else that he or she should choose death with dignity. My question is: Who has the right to tell me that I don't deserve this choice? That I deserve to suffer for weeks or months in tremendous amounts of physical and emotional pain? Why should anyone have the right to make that choice for me? Now that I've had the prescription filled and it's in my possession, I have experienced a tremendous sense of relief. And if I decide to change my mind about taking the medication, I will not take it. Having this choice at the end of my life has become incredibly important. It has given me a sense of peace during a tumultuous time that otherwise would be dominated by fear, uncertainty and pain.

Her case received a great deal of publicity, and widespread report. Among the statements that expressed concerns or outright condemnation, were the following.

Dr. Jauhar, a cardiologist, while supporting assisted suicide in ‘rare cases’ wrote the following on a CNN opinion piece:

> However, I still believe that for most terminally ill patients, hospice care is a better option than assisted suicide. Hospice offers team-based care with family involvement, often in a patient's home, that focuses on pain management and dying with some comfort and dignity. Hospice staff is available 24 hours a day, seven days a week.

Matt Walsh, in *The Blaze* wrote:

> Across national media and social media, I've been sickened to see that suicide is now most commonly described with words like 'dignity,' 'bravery,' 'courage,' and 'strength.' Popular refrains apparently only ever used to justify some form of murder and destruction have been trotted out once again: 'it's her body,' 'it's her choice,' 'it's her life.' If you read the comments under most articles about this case, you'll find a horrifying and blind adoration for euthanasia, with adjectives and phrases applied to Brittany that we usually reserve for war heroes and martyrs. But I guess, in our modern enlightened society, Brittany Maynard *is* a martyr. She is a martyr for the cause of self-destruction. I am terrified to think that my children will grow up in a culture that openly venerates suicide with this much unyielding passion. [It is] necessary for those of us who oppose the Culture of Death to speak up and say something here. … Every noble ideal — justice, fairness, equity, compassion, charity — all of it, *all of it*, is grounded in the notion that life, human life, has intrinsic value. Not value according to its usefulness, or value according to convenience, or value according to how enjoyable it is. Value. Life is valuable because it is life. If you deny this, then you deny everything.

People magazine reported that a Vatican official condemned Brittany Maynard, the terminally ill woman who ended her own life November 1st, 2014 . Monsignor Ignacio Carrasco de Paula, the President of the Pontifical Academy for Life, called Maynard's assisted suicide "an absurdity:"

> This woman [took her own life] thinking she would die with dignity, but this is the error. Suicide is not a good thing. It is a bad thing because it is saying no to life and to everything it means with respect to our mission in the world and toward those around us.

<u>Questions:</u>

1. Do terminally ill people have the moral right to end their own lives when they choose? Should they have the legal right? What restrictions should be put on such a right?

2. The primary duty of a doctor, it is often said, is *primum non nocere* – first of all, do no harm. Is prescribing a lethal dose of a medicine to a terminally ill patient harming that patient? If not, why?

3. Critics of assisted suicide sometimes worry that we are starting on a slippery slope that may lead to involuntary euthanasia. Is there such a danger, and what might we do to prevent it?

References:

Corriston, M. (2014, November 4). Vatican Official Condemns Brittany Maynard's Decision to Die. Retrieved January 19, 2015, from http://www.people.com/article/vatican-official-condemns-brittany-maynard

Jauhar, S. (2014, October 8). When assisted suicide is not the answer. Retrieved January 19, 2015, from http://www.cnn.com/2014/10/08/opinion/jauhar-assisted-suicide-hospice-option/index.html

Maynard, B. (2014, November 2). My right to death with dignity at 29. Retrieved January 19, 2015, from http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/index.html

Walsh, M. (2014, October 9). There Is Nothing Brave About Suicide. Retrieved January 19, 2015, from http://www.theblaze.com/contributions/there-is-nothing-brave-about-suicide/

CASE 3
Addicted Physicians Allowed to Treat

Before 1980, if physicians displayed signs of having a substance abuse problem, they were stripped of their medical license and prevented from practicing, at least until they proved to have recovered. Getting a DUI, going to rehab, or being arrested for drug possession threatened the careers of medical professionals. The rationale behind this rule was the protection of patients, but some argued that it had the side effect of preventing physicians from getting help for existing problems. Instead, physicians had to hide their substance abuse problem for fear of losing their livelihood.

Now however, most states have programs by which physicians can get anonymous help for abuse problems, and retain their medical licenses as long as they remain in compliance with the program. This means that many physicians are able to get the help that they need without fear that enrolling in a treatment program could damage their livelihood. Estimates suggest that 8,000 physicians may be enrolled in these programs nationwide.

Recently, there have been many high-profile cases of intoxicated physicians in treatment programs botching medical procedures. Some physicians did not follow up with their patients on abnormal cancer test results, and some failed at procedures such as gastric bypasses and mastectomies. As a result, California abolished its confidential treatment program. State analyses of the California's treatment program showed that it was not helping physicians to recover from addiction, and it raised concern that the anonymous nature of the programs prevents patients from protecting themselves against going to potentially compromised physicians for medical treatment.

Critics of the move claim that this will force physicians with substance abuse programs to hide their addictions and prevent them from seeking treatment, thus placing patients at greater risk of harm. They point out that these high-profile cases involved physicians who were not in compliance with treatment programs. However, because an estimated 10-15% of physicians will have substance abuse problems in their lifetimes, the president of California's Medical Board points out that many feel uncomfortable "hiding" a physician's potential incapacity as a medical professional.

Questions:

1. Is it ethical to hide information about the status of physicians as in-treatment from patients? How much relevant information about a doctor's personal life is a patient entitled to?

2. Should physicians who cannot get clean have their medical licenses revoked, even if there is no direct evidence that their addiction has impacted their professional performance?

3. What right to privacy about things like DUIs or possession charges do physicians have, even if they are not currently in treatment? What responsibility does the medical establishment have to physicians to make it possible for them to pursue improving their lives with things like treatment programs, and how should these be discharged?

Resource:

Wohlsen, M. (2007, December 19). Addicted Doctors Are Allowed to Practice. Retrieved January 19, 2015, from http://usatoday30.usatoday.com/news/health/2007-12-19-1581797083_x.htm

CASE 4
Suppression of Puberty for Transgender Teens

When Violet's parents tell the story of her transition, it all begins with an old Minnie Mouse dress. The family had purchased the dress for Violet's older sister on a trip to Disneyland. When she was only 2 years old, Violet found the dress, put it on, and refused to take it off. According to Violet's mother, "[Violet] pretty much slept in it, stayed in it all day," and any attempt to remove the dress would provoke an outburst.

For the first few years, Violet's parents tried to steer her away from feminine clothing. By the time Violet was 5, her parents had implemented what they called an "only-in-the-house" policy, and for a time Violet seemed content with it. But one day, her father came home to find her in the front yard, wearing a poodle skirt, dancing and singing.

Her parents were worried and afraid. They feared that Violet would be the object of ridicule. They feared that she would be bullied or the victim of violence. The more they tried to police Violet's gender expression, the more explosive Violet's behavior became. Her parents describe two-hour tantrums and tornadoes of tears. Violet's father says, "The terrible twos became the terrible threes and fours and horrible fives and intolerable sixes."

Violet's parents, concerned about her overall wellbeing, sought help from mental health professionals, but it was several years before they found a psychologist who had experience with gender issues. At the age of 11, Violet was diagnosed with gender identity disorder. Violet's parents say they immediately stopped trying to force her to live as a boy. The relief that came with the diagnosis was followed with a new anxiety, however. Violet's father says, "We knew that puberty was around the corner, and we needed to start looking into … what do we do. How do we help this child, you know, develop in a way that is consistent with who she is."

In recent years, a new treatment has become available for adolescents with gender identity disorder. Doctors are able to suppress the onset of puberty with monthly injections of drugs that block the production of sex hormones. Although the technique has been used for decades to treat adult patients in a variety of cases, it was first used in the Netherlands to treat children like Violet about 17 years ago.

Norman Spack is an endocrinologist at Children's Hospital in Boston and one of the earliest adopters of this treatment in the United States. Spack explains, "If you can block the gonads, that the ovary [in women] or the testis [in men], from making sex steroids, that being estrogen or testosterone, then you can literally prevent … almost all the physical differences between the genders."

Many transgender young adults describe the puberty as alienating—a time when their bodies betray them. Suppressing puberty means that males will not develop an Adam's apple and will not grow facial or other body hair. Their voices will not deepen. By blocking the production of estrogen, females will not develop breasts and will not begin menstruation. Around the age of 16, individuals decide whether to move to a second stage of treatment and begin hormone therapy.

Supporters of the treatment argue that the suppression of puberty gives children and their families time to determine a course of action and, if hormone treatment is selected, the best possible chance at transition. Some opponents of the practice argue that gender identity in children is constantly in flux and that suppression of puberty is not in a child's best interests.

Others argue that treatment is unethical because taking testosterone or estrogen immediately after blocking puberty will result in infertility. Since the gonads do not mature before they are exposed to hormone treatment, they become too damaged to produce viable eggs or sperm. These opponents argue that 16-year-olds are too young to make health decisions that will result in lifelong infertility.

Questions:

1. Is it morally permissible to suspend the puberty of children with gender identity disorder? Is it morally obligatory?

2. Are children and adolescents with gender identity disorder able to make informed choices about their care?

3. Is it the role of the healthcare system or the state to interfere in the treatment process of children and adolescents with gender identity disorder? What are the roles of the parents, doctors, and adolescent patients in this situation?

[Case developed from "Parents Consider Treatment to Delay Son's Puberty," National Public Radio, May 8, 2008]

CASE 5
Transplant Tourism: It's No Vacation

Mr. Charles is a 45 year old man with hepatitis B virus, cirrhosis, and liver cancer. He was listed for liver transplantation for over a year but did not receive a donor organ through the local organ procurement organization. After searching on the internet, Mr. Charles discovered that he could receive a partial liver transplant from a living donor in Costa Rica for a fee, and so he made all the necessary arrangements, traveled to Costa Rica, and received a transplant.

A few months later, Mr. Charles returned to the hospital for follow-up care. He presented with fever, weakness, and lethargy. He was found to have developed sepsis due to bile duct problems and hepatic artery thrombosis. These problems are likely a result of the liver transplant he received in Costa Rica. The only option for Mr. Charles is to be listed again for a re-transplant in the United States with the same local organ procurement organization. Because Mr. Charles is seriously ill, if he is listed he would have high priority on the transplant waiting list. If he is not listed, he will very likely die from liver failure.

The transplant team is divided on whether or not Mr. Charles should be relisted for a liver transplant. He insisted that his liver was from a Good Samaritan donor and provided an affidavit from the transplant surgeon ensuring that his fee would not be used to compensate the donor. However, the doctors and healthcare team are all aware of recent arrests of physicians and their associates by the Costa Rican FBI in connection with organ trafficking. The two associates, a taxi driver and a small business owner, recruited poor Costa Ricans to be live organ donors in exchange for monetary compensation. The operation was extensive and included forged legal documents, international brokers, and intimidation of physicians who were hesitant or unwilling to perform the transplants. The known donors, many of whom did not receive post-operative care, have since been placed in a government protection program.

Based on this information, there is a good chance that Mr. Charles' transplant was conducted illegally and unethically. Some of the transplant team members believe that being the beneficiary of trafficked organs disqualifies Mr. Charles from rejoining the transplant list. Others believe that, regardless of how the organ was obtained, they have an obligation to provide the best treatment possible for their patient.

Questions:

1. What are the moral considerations that determine whether Mr. Charles should be relisted for a new liver transplant? Should he be relisted? In general, should patients who receive a transplanted organ overseas be disqualified from re-transplants?

2. What ethical obligations, if any, do physicians have with respect to organ tourism and international organ trafficking? For example, physicians have obligations to help their patients receive the best care possible, and to provide their patients with current medical information. Does this include informing patients of potential options for obtaining a transplanted organ in a different country, with advice on which programs have good success rates? Do physicians have obligations to report their patients to legal authorities if they return from an overseas trip with a transplanted organ, or if they state their intentions to travel overseas for an organ?

3. Should a regulated market for transplant organs be established in the United States? Why or why not, and if so, what sorts of regulations or constraints should be imposed on this market?

This case is a fictional adaptation of the following two cases:

Sack, Kevin. "Transplant Brokers in Israel Lure Desperate Kidney Patients to Costa Rica." New York Times, Aug 17 2014. http://www.nytimes.com/2014/08/17/world/middleeast/transplant-brokers-in-israel-lure-desperate-kidney-patients-to-costa-rica.html?_r=0

Rhodes, Rosamond & Thomas Schiano 2010. Transplant tourism in China: A tale of two transplants. The American Journal of Bioethics, 10(2): 3-11.

CASE 6
Refusing to Force-Feed Detainees at Guantanamo Bay

In early 2013, prisoners in the Guantanamo Bay detention camp went on a hunger strike to protest inmate mistreatment in the prison. The spark for the protest may have been the sense among prisoners that they would never go home. Many of the prisoners were being detained indefinitely without trial. Others were cleared of any connection to terrorism and were not criminally convicted, but the United States military failed to release them after twelve years.[1] During the hunger strike, Navy nurses were called to force-feed protesting inmates. This practice is painful for inmates, as it involves forcing a liquid nutrient mix through a nasogastric feeding tube. The inmates are restrained in chairs for the duration of the feeding.

In July 2014, a Navy medical officer refused to participate in the force-feeding of Guantanamo Bay inmates. The officer initially volunteered to serve at Guantanamo, but after carrying out force-feedings, he refused to participate further in the practice. As a result, he was informed that he might be the subject of an internal military investigation. The officer, a nurse and 18-year Navy veteran, now faces possible punishment or discharge (either honorably or dishonorably). The consequences of such a discharge would be devastating, as he could possibly lose his pension and other veteran's benefits. The discharge would also send a message to other Navy medical officers that refusal to participate in force-feeding could end their careers.

Defenders of the practice argue that they have a responsibility to maintain the lives of the detainees. As President Obama explained in a press conference, "I don't want these individuals to die."[2] Additionally, some argue that the stress of incarceration may distort the rational capacities of inmates and increase the likelihood of self-destructive behavior. According to this view, the detention camp staff has an ethical obligation to keep inmates alive through force-feeding. However, this type of justification may require psychiatric evaluations, patient education and counseling, and careful medical monitoring.[3] The goal of force-feeding would be for inmates to resume normal eating.

Opponents of force-feeding see it as an inhumane and torturous practice that violates an individual's autonomy and dignity. Hunger strikers view their refusal to eat as their only way to protest imprisonment peacefully. If the inmates are to be viewed as autonomous individuals, they

[1] Charlie Savage, "Guantánamo Prison Revolt Driven by Inmates' Despair," *The New York Times*, April 24, 2013, sec. U.S., http://www.nytimes.com/2013/04/25/us/guantanamo-prison-revolt-driven-by-inmates-despair.html; "The Ethics of Force-Feeding Inmates," *The New York Times*, May 1, 2013, http://www.nytimes.com/roomfordebate/2013/05/01/the-ethics-of-force-feeding-inmates.
[2] "The Ethics of Force-Feeding Inmates."
[3] Ibid.

possess the right to decide not to eat, and force-feeding constitutes a violation of autonomy.[4] Several organizations have condemned force-feeding, including the American Medical Association which called the practice a violation of "core ethical values of the medical profession," and stated that "every competent patient has the right to refuse medical intervention". The American Nurses Association appealed to professional ethics, stating that "the ethical right of a professional nurse to make an independent judgment about whether he or she should participate in this or any other such activity ought to be protected."[5]

No decision has been made regarding the potential punishment of the Navy medical officer.

Questions:

1. Is force-feeding detainees who are on a hunger strike morally justified?

2. Does the United States military possess an ethical obligation to maintain the health of Guantanamo Bay inmates?

3. Do medical professionals have the right to refuse to participate in the practice of force-feeding? Does the Navy medical officer, as a military official, have a greater duty than would a non-military medical professional to carry out the force-feedings?

[4] Ibid.

[5] Benedict Carey, "Nurses Urge Leniency over Refusal to Force-Feed at Guantánamo Bay," *The New York Times*, November 19, 2014, http://www.nytimes.com/2014/11/20/health/nurses-urge-leniency-over-refusal-to-force-feed-at-guantnamo-bay.html.

CASE 7
Informed Consent for Organ Donation

Elijah Smith, a 21-year old new father, was hit by a car while riding his bicycle on July 3rd, 2013. The following day, he was declared dead by neurological criteria (or "brain dead") at Grant Medical Center in Ohio.

Elijah was a registered organ donor. Like many others, he registered when he applied for his driver's license and was subsequently enrolled with Lifeline of Ohio, the local organ procurement organization. Once Elijah was declared dead by neurological criteria, Grant Medical Center notified Lifeline to begin the process of organ procurement. However, when his parents, Pamela and Rodney Smith, learned that organ removal takes place while the donor remains on mechanical ventilation during the surgery, they attempted to block Lifeline from procuring Elijah's organs.

According to Mrs. Smith, Elijah did not understand to what he was agreeing when he registered as an organ donor. She argued that he was not aware of the process of organ removal, particularly that it takes place while the donor remains on mechanical ventilation during the surgery. If Elijah had understood the process, she argued, he would not have registered as an organ donor. "We do not want our son to die like this," Mrs. Smith wrote to Lifeline. "We do not want our son to be an organ donor."[1]

According to the Columbus Dispatch, the Smith family wanted to see Elijah unplugged from the mechanical ventilator to see him "die completely", "so that we could accept that we did everything that we could. We were still hoping against hope that he would breathe. We knew that wasn't very likely."[2]

Mrs. Smith's appeal led Grant Medical Center to deny Lifeline access to Elijah's organs without a court order. Since Ohio law prohibits the reversal of a donor's decision by anyone besides the donor, a court order was obtained on July 11th, and Lifeline continued with the organ procurement process, over the objections of Elijah's parents.

[1] Allison Manning, "Family Loses Fight to Keep Son's Organs from Donation," *The Columbus Dispatch*, July 12, 2013, http://www.dispatch.com/content/stories/local/2013/07/11/Judge-ordered-family-to-let-brain-dead-son-donate-organs.html.

[2] Misti Crane, "Dispute over Organ Donation Brings Attention to Defining Death," *The Columbus Dispatch*, July 22, 2013, http://www.dispatch.com/content/stories/local/2013/07/22/dispute-over-organ-donation-brings-attention-to-defining-death.html.

Mrs. Smith described "brain death" as "a convenient way to facilitate the donation of [Elijah's] organs."[3] Though she felt Lifeline had "gone behind our backs…to get my son's organs,"[4] she did not take further action. Mrs. Smith said that she wants more people to better understand the process of organ donation, and to discuss their wishes with their families. "It's not that we're against organ donation," Mrs. Smith said, "We just don't like the way it's done."[5]

According to Lifeline's chief clinical executive, this was the first time the organization has obtained a court order to recover organs over a family's objection.

Questions:

1. Should a family or other surrogate decision-maker be allowed to challenge and overturn an organ donor's decision to donate organs? Consider also the reverse situation: If Elijah had not registered as an organ donor, should his family have the authority to agree to donate his organs on his behalf? Is there an asymmetry between surrogate consent to donate and surrogate refusal to donate?

2. If Elijah was ill-informed of the process of organ donation, as his mother argued, was his registration as an organ donor valid? What should be the criteria for a valid advance directive to donate organs? Should the criteria be simple authorization (in other words, a gift), without the more substantial level of understanding required of true informed consent? What information should be disclosed before a person agrees to organ donation, based on your proposed criteria? For example, do people need to understand the differences between donation after brain death and donation after cardiac death? Do they need to understand that there is debate in the academic community about whether brain death is equivalent to death?

3. Despite being entrenched in medical and legal practice for many years, the equivalence of "brain death" with death remains controversial, with some scholars arguing that brain death does not meet any established biological concept of death. What implications, if any, does this controversy have for the established practices of organ donation and the declaration of brain death? For example, should families or patients be granted exceptions to declaring death by neurological criteria if they do not accept brain death? If any exceptions are allowed, what are the limits?

[3] Manning, "Family Loses Fight to Keep Son's Organs from Donation."
[4] Ibid.
[5] Crane, "Dispute over Organ Donation Brings Attention to Defining Death."

CASE 8
Charlie's Mangled: Concussions, College, and High School Football

Charlie is a seventeen year old who plays varsity football in rural Georgia, and he is about to enter his senior year of high school. He has played football for most of his life, beginning in elementary school. Charlie's parents are avid football fans, and they signed him up for a recreational league in fifth grade so that he would learn certain values through team sports, such as teamwork, determination, and perseverance. Charlie quickly became a star athlete for his team. He greatly enjoyed the accolades he received and continued to play football throughout middle school and high school, eventually becoming a varsity player during his 9th grade year.

Several colleges are recruiting Charlie, and they could potentially offer him a scholarship if he maintains the same high level of play during his senior year as he did during his junior year. However, Charlie has sustained several concussions throughout his football career. Doctors told him over the summer that, due to his prior concussions, he has an increased risk of dementia, depression, and, later in his life, symptoms similar to those of Parkinson's disease. Further, he is more susceptible to additional concussions, which are likely to cause more serious neurological damage.

Without a football scholarship, Charlie may not be able to attend college. Charlie's parents are unable to support him further, and they have not saved up enough money to pay for his college tuition. Charlie is not academically gifted enough to receive a merit-based scholarship. Despite his doctor's warnings, Charlie currently experiences no physiological or psychological symptoms and plans to continue playing football during his senior year of high school. For Charlie, continuing to play football is crucial to both his enjoyment of his last year in high school, as well as his potential to attend college and secure a stable job. This year, Charlie may be able to help his football team win a state championship for the first time. Furthermore, Charlie has the potential to succeed in collegiate football and continue on to playing professionally. As a result, he discounts the very real risk that he might be greatly jeopardizing his quality of life in order to play football. Charlie's parents recognize the significant health risks of allowing Charlie to continue playing football, but they also realize that, without football, Charlie may not have any other opportunities to attend college and secure a stable job. His parents do not know whether to allow their son to continue playing football.

Questions:

1. Taking into account the above information, should the physicians, Charlie's parents, or school administrators step in to prevent Charlie from playing his senior year?

2. Should parents be allowed to let their children play contact sports at early ages like Charlie, given the possibility for serious head injuries and other injuries as well?

3. Knowing that there are many others who have similar experiences to Charlie's, should the rules of contact sports be changed in order to reduce the risk of head injuries and their accompanying long-term effects?

CASE 9
The Great Esc-Ape: Personhood and Chimpanzees

Tommy is a 26-year-old chimpanzee who spent most of his early life traveling in a circus. In 2004, he was sold to reindeer rancher Patrick Lavery, who ever since has mostly kept Tommy in a cage inside a warehouse. Tommy no longer participates in travel and training of the circus, and he is now relatively isolated in his cage, accompanied by a small portable television. He interacts with Lavery and other humans for a few minutes per day.[1] In December 2013, Steven M. Wise, a legal scholar and co-founder of the Nonhuman Rights Project (NhRP), filed suit on Tommy's behalf, arguing that he had been wrongfully imprisoned.

The legal argument is that Wise should be allowed to petition a court for a writ of *habeas corpus*, which would then summon Lavery to justify Tommy's imprisonment in a court of law. To petition for a writ of *habeas corpus* requires that Tommy be considered a person before the law; it has not yet been argued that Lavery has treated Tommy cruelly. If released, Tommy would be transplanted to a primate sanctuary in Florida where he would live on an artificial island with other chimpanzees. The litigation was recently considered by the New York general ("Supreme") court, then appealed and rejected by that court's Appellate Division. Wise plans a final 2015 appeal to the New York's highest court, the Court of Appeals.

Citing affidavits from nine primatologists, Wise argued that chimpanzees such as Tommy should be considered legal persons because they exhibit highly complex cognitive functions—notably autonomy, self-awareness, and self-determination, including the ability to make conscious choices about their lives through conceiving of their own past and future.

The Appellate Division ruled that Tommy was not entitled to personhood because he was not able to act on societal obligations or duties.[2] That is, they ruled that reciprocity between rights and responsibilities "stems from principles of social contract: . . . rights [are] connected to moral agency and the ability to accept societal responsibility in exchange for [those] rights." They cited *Black's Law Dictionary'*s definition of 'person' as "[a]n entity (such as a corporation) that is recognized by law as having the rights and duties [of] a human being."

One main criticism has been that the ruling is logically committed to denying to many humans the same rights denied to Tommy. Many cognitively disabled, juvenile, senile, and comatose

[1] See: Nicholas Fleur, "Chimps Aren't People—for Now," *The Atlantic*, December 9, 2014, accessed December 30, 2014, <http://www.theatlantic.com/politics/archive/2014/12/why-a-court-ruled-chimps-arent-people/383463/>; Michael Mountain, "Appellate Court Hearing in Tommy Case", NhRP website, October 9, 2014, accessed December 30, 2014, <http://www.nonhumanrightsproject.org/2014/10/09/appellate-court-hearing-in-tommy-case/>; Brandon Keim, "Case for Chimpanzee Rights Rejected by Appeals Court," *Wired.com*, December 4, 2014, accessed December 30, 2014, < http://www.wired.com/2014/12/court-says-chimp-not-a-person/>.

[2] *NhRP v. Lavery*, New York State Supreme Court, Appellate Division, Third Department, No. 518336, December 4, 2014, accessed December 30, 2014, < http://decisions.courts.state.ny.us/ad3/Decisions/2014/518336.pdf>.

humans lack, at least in part, moral agency or capacity to guide behavior in accordance with duty. The court responded to this objection:

> To be sure, some humans are less able to bear legal duties or responsibilities than others. These differences do not alter our analysis, as it is undeniable that, collectively, human beings possess the unique ability to bear legal responsibility. Accordingly, nothing in this decision should be read as limiting the rights of human beings in the context of habeas corpus proceedings or otherwise.

To critics, this statement may seem discriminatory. Proponents, on the other hand, may only support extending rights of personhood to an entire species, rather than to individual members of a species. In this view, one would ascribe personhood to a species on the basis of the typical (rather than exceptional) moral agency of that species' members.

An additional issue concerns whether there must be a sharp moral or legal distinction between human and nonhuman animals. Critics of the NhRP's position have argued that granting rights or personhood to chimpanzees would create a slippery slope: courts would be forced logically to extend personhood to other animals or even to autonomous machines. To Wise and the NhRP, this is largely a welcome result, as they have already planned similar litigation on behalf of other primates, elephants, dolphins, and whales. Wise argues that, although autonomy should not the only basis for legal protections, it is "the head of the battering ram" that can break through the legal wall separating humans from all other animals. He says this will 'change the discussion' from the question 'What species are you?' to "'What sort of being are you? . . . Are you the kind of being who ought to have the potential for any rights at all? And if so, what rights are appropriate for you?"[3]

<u>Questions</u>

1. As a purely moral matter, should Tommy be thought to have a right against involuntary imprisonment? Should he be considered a person? What ethical considerations bear on this?

2. Do you agree with the court's assessment that the capacity to have rights depends on the capacity to comply with duties? Why or why not?

3. Do you agree with their assessment that rights apply to members of the human species collectively? Why or why not?

[3] Brandon Keim, "New York State Court Hears Landmark Chimp Personhood Case," *Wired.com*, October 9, 2014, accessed December 30, 2014, < http://www.wired.com/2014/10/chimpanzee-personhood-hearing/>.

CASE 10
Sex, Stigma, and Federal Guidelines for the Prescription of PrEP

On May 14, 2014, the United States Public Health Service issued the first set of comprehensive clinical practice guidelines for pre-exposure prophylaxis (PrEP). Studies indicate that Truvada, a single capsule containing tenofovir and emtricitabine, is highly effective at preventing HIV in individuals with "substantial risk" of infection through sexual activity or recreational injection drug use. According to the guidelines, an individual is at substantial risk of infection if they are:

1. in an ongoing relationship with an HIV-positive partner
2. not in a mutually monogamous relationship with an HIV-negative partner
3. a gay or bisexual man who has (a) had anal sex without a condom or (b) been diagnosed with a sexually transmitted infection in the past six months
4. a straight man or woman who does not regularly use condoms with a partner, if that partner (a) has an unknown HIV status and (b) is at substantial risk of infection (drug users and those with bisexual male partners)
5. less than six months removed from their last use of illicit drugs
6. in the habit of sharing needles
7. less than six months removed from a drug rehabilitation or treatment program.

In order to begin PrEP, an individual's status as HIV negative must be confirmed. A physician will then encourage condom use for additional protection and refer the individual to further educational and counseling resources. The individual is strongly encouraged to seek blood tests every three months to monitor HIV status and side effects.

Records indicate physicians in cities such as New York, San Francisco, and Chicago are leading the charge to prescribe PrEP. Many reputable LGBT interest groups have endorsed PrEP. However, some public health officials have speculated that PrEP will create a false sense of security among gay and bisexual men, decrease or replace regular condom use, and lead to greater incidence of non-HIV sexually transmitted infections. Other public health officials question the singling-out of men who have sex with men in the first place. They point out that the first and second criteria are geared toward those (presumably heterosexual individuals) in some semblance of a long-term relationship. The fourth criterion seeks to protect heterosexuals who have sexual contact with bisexual men, while the third criterion expressly endorses PrEP on the presumed behaviors of non-heterosexuals. Thus, self-confessed "radical queer" commentators trace part of the federal government's PrEP guidelines to the moral panic that corresponded to the declaration of the "AIDS epidemic" in the 1980s-1990s. Health advocates, including the Centers for Disease Control and Prevention, anticipate this criticism by developing "community-specific" protocols for "population-based" healthcare recommendations.

Questions

1. Should federal PrEP guidelines be rewritten to remove references to sexual orientation? Is the inclusion of sexual orientation a legitimate means of ensuring public health or does it contribute to the depiction of HIV/AIDS as a "gay disease"?

2. "Population-based" approaches to healthcare tend to limit the willingness or the capacity of physicians to meet the needs of patients that run counter to federal guidelines. Are there alternative approaches to reducing HIV infections (and if so, what are they?) or is the naming of gay and bisexual men as disease vectors an unfortunate byproduct of good public health?

3. African Americans account for 506,000 of the 1.1 million cases of HIV/AIDS in the United States. Should federal guidelines be rewritten to identify sexually active African Americans as a "substantially at-risk" group like men who have sex with men? Why or why not?

Sources:

Bridges, Khiara. *Reproducing Race: An Ethnography of Pregnancy as a Site of Racialization.* Berkeley: University of California Press, 2011.

Centers for Disease Control and Prevention. (2014, September 30). Pre-Exposure Prophylaxis (PrEP). Retrieved from http://www.cdc.gov/hiv/prevention/research/prep/

Kaiser Family Foundation. (2014, April 25). Black Americans and HIV/AIDS. Retrieved from http://kff.org/disparities-policy/fact-sheet/black-americans-and-hiv-aids/

CASE 11
Dale Refuses His Psychotropic Medications

Dr. Phillip Draney is a psychiatrist employed at a maximum-security prison. Dale Strickland has been convicted of assault charges and will be held at the prison for the next fifteen years, and he is up for parole after eight. Records from both the prosecution's and the defense's mental health evaluations are included in Strickland's health file, to which Dr. Draney has access. The court proceedings and medical records show that mental health professionals from both the prosecution and the defense diagnosed Dale with Borderline Personality Disorder. While this diagnosis includes delusions, irritability, mood swings, and, in some cases, violent behavior, he was still deemed by all parties fit to stand trial for his crimes.

Since he has been held at the maximum-security facility, Dale has been involved in a series of violent altercations. The incidents have included intimidation, assault, and sexual abuse of other inmates. Prison wardens and guards have advised Dr. Draney to put Dale on psychotropic medications to curtail this behavior, as the behavior is caused, at least partially, by his mental illness. The prison possesses legal rights to administer forcibly psychotropic drugs if the patient poses a threat to himself or to other inmates, and if no other options treatment options exist.

Dale insists that it is within his rights to refuse treatment if there are other options. Dale accepts his mental health diagnosis, but he demands that he meet with a mental health counselor three times a week rather than take psychotropic medications against his will. However, Dr. Draney is the only mental health technician currently employed by the prison who is qualified to engage in one-on-one psychological counseling with inmates, and he does not have time to meet with Dale so frequently. Nevertheless, Dale insists that counseling, rather than medication, will be the most effective treatment regime. Further, Dr. Draney knows that Borderline Personality Disorder is often not directly responsive to psychotropic medications alone. However, there are a variety of medications that will likely reduce Dale's violent outbursts, at least for the short term, and thus reduce his threat to other inmates.

Questions:

1. Should Dr. Draney put Dale on psychotropic drugs against his wishes? Why or why not? And if so, how?

2. Should Dale have the right to refuse psychotropic drugs if mental health counseling resources become available to him? Why or why not?

3. If Dale were not an inmate, should he have a right to refuse treatment? If Dale were merely charged and still awaiting trial, should he have a right to refuse treatment? What bearing does Dale's status as a prisoner have on the ethical issues of this case?

Resources:

Rennie v. Klein, 653 F.2d 836 (3d Cir. 1981).

Washington v. Harper, 494 U.S. 210, 110 S. Ct. 1028, 108 L. Ed. 2d 178 (1990).

Riggins v. Nevada, 504 U.S. 127, 112 S. Ct. 1810, 118 L. Ed. 2d 479 (1992).

Rogers v. Okin, 738 F.2d 1 (1st Cir. 1984).

CASE 12
Love Potion Number 9

Maintaining happy, long-term relationships can be difficult, as is evident from high rates of divorce in the U. S. and other Western countries. While couples can deal with problems in their relationships in ways such marriage counselling, advances in the neurobiology of love, attachment, and "pair bonding" may lead to another way of dealing with these problems.

Research on substances like oxytocin and vasopressin suggests that these substances play an important role in attachment and "pair bonding" in mammals, including humans.[1] As research on these substances advances, the knowledge that comes from this research may provide a way to develop a pill that could help people help people form and maintain attachments with each other.

Suppose pharmaceutical companies develop a pill for what they call the "neuroenhancement" of love, relationships, and marriage. This pill would not necessarily make a people fall in love, produce a perpetual state of infatuation, or solve all of the problems in a couple's relationship. However, research has shown that substances like oxytocin and vasopressin encourage bonding activity like spending time together and communicating effectively. These substances also help people to develop positive emotional associations toward their relationships. Just as couples take many other steps such as marriage counseling to improve their relationships, research suggests that such a drug might offer another way to strengthen people's attachments.

The potential benefits of such a pill are obvious. For people who want to strengthen their relationships, this pill provides a means to do so. Since the pill helps people to develop positive emotional associations toward their relationships, people who take this pill might enjoy their relationships more.

However, this pill also raises some concerns.[2] One concern is that this pill might make the love between two people inauthentic. If feelings of attachment and love are results of medication, then perhaps these feelings do not reflect the quality of a relationship or the good qualities of the person at whom these feelings are directed. Another concern is that that taking this pill might cause some people to remain in relationships that are so bad that these people should leave these relationships rather than take a pill to make these relationships more bearable. One particularly bad scenario could be that in an abusive relationship, one person might coerce his or her partner into taking this pill into order to help keep his or her partner from leaving the relationship.

[1] Savulescu, J., & Sandberg, A. (2008). Neuroenhancement of love and marriage: the chemicals between us. *Neuroethics*, *1*(1), 31-44.
[2] Ibid.

Suppose the pill has no medically dangerous side effects.

Questions:

1. Suppose the love pill exists. Should the state regulate or ban this pill?

2. Are there any morally significant differences between taking this pill and pursuing traditional routes to strengthening a relationship, such as counseling? If so, what are these differences?

3. Imagine that one could use this pill to strengthen one's attachment to one's child. Would the use of the pill for parent-child relationships be morally different from the use of the pill for romantic relationships?

CASE 13
The Dallas Buyers Club Law

Larry Kutt, age 65, lives in a small town in Colorado on the edge of the Rocky Mountains. Mr. Kutt suffers from advanced multiple myeloma, a form of blood cancer, and he has exhausted all available approved treatment options. His prognosis is bleak, but he holds out hope now that a new 'Right to Try' law has passed in Colorado.

'Right to Try' laws were introduced in at least 10 states in 2014. These laws grant terminally ill patients the right to petition drug companies directly for access to unapproved treatments, provided that the treatment in question has passed the first phase of the FDA-required drug trials. Under normal circumstances, patients only have access to unapproved treatments through participation in clinical trials. Terminally ill patients and their families are overwhelmingly in favor of the law. Mr. Kutt, in an interview with the New York Times, stated, "It's my life and I want a chance to save it."

'Right to Try' bills have passed into law with little (and in some cases) no opposition. Critics of these laws point out that they are not all that they seem to be. First, The FDA already has a process in place for granting unapproved therapies for people with exceptional need. Second, while 'Right to Try' laws grant patients the right to petition drug companies directly, the companies have no legal obligation to provide the patients with the requested treatment. Further, the laws do not mandate that insurance companies cover the unapproved treatments.

Questions:

1. Do pharmaceutical companies have an obligation to make experimental drugs available to patients before those treatments have been given FDA approval?

2. Do patients have a right to unapproved treatments? If so, at what point during the course of disease progression and treatment should a patient be able to access these treatments?

3. Should 'Right to Try' laws only apply to certain medical conditions? How might physical and mental symptoms (e.g., loss of mental capacities or inability to self-administer medications) be morally relevant in this case? What limitations should apply to these laws?

Source:

Julie Turkewitz, "Patients Seek 'Right to Try' New Drugs," *New York Times*, January 10, 2015, accessed January 12, 2014, http://www.nytimes.com/2015/01/11/us/patients-seek-right-to-try-new-drugs.html?_r=0

Further Resources:

"'Right to try' law gives terminal patients access to drugs not approved by FDA," *PBS NewsHour*, June 21, 2014, http://www.pbs.org/newshour/bb/right-try-law-gives-terminal-patients-access-non-fda-approved-drugs/

"The FDA's Drug Review Process: Ensuring Drugs are Safe and Effective," *Federal Drug Administration*, last modified November 6, 2014, http://www.fda.gov/Drugs/ResourcesForYou/Consumers/ucm143534.htm

CASE 14
The Case of Cassandra C.

In January 2015, the Connecticut Supreme Court ruled that a 17-year-old girl does not have the right to refuse chemotherapy. In September 2014, Cassandra was diagnosed with advanced (stage 3 or 4) Hodgkin's lymphoma. After undergoing surgery to remove part of her lymph node, Cassandra's doctors moved to start her on a course of chemotherapy, which has an 80 to 95 percent success rate in treating Hodgkin's lymphoma. Without chemotherapy, her doctors agree that Cassandra will likely die within two years.

Worried about the possible long-term side effects of chemotherapy, which include heart damage and infertility, Cassandra and her mother left the hospital against medical advice, and Cassandra refused further treatment. In accordance with Connecticut law, Cassandra's doctors reported her mother to the Department of Children and Families (DCF), as they would any other case of suspected child abuse or neglect. DCF took the case to the state Superior Court. In November, the court granted DCF temporary custody of Cassandra and placed her in temporary foster care.

After being removed from her home, Cassandra agreed to undergo chemotherapy on the condition that DCF allow her to return home. After only two chemotherapy treatments, Cassandra decided that she could not continue it. Feeling that she had no other options, Cassandra ran away from home. The case went back to court in December, and Cassandra was removed from her home by DCF a second time. She has been forcibly hospitalized and undergoing court-ordered chemotherapy since December 2014.

Cassandra and her mother appealed to the state Supreme Court. In the appeal, Cassandra's lawyer argued, "Absent any finding that they [Cassandra and her mother] are incompetent, the trial court violated their constitutional rights in allowing DCF to substitute its judgment for theirs and in permitting DCF to force Cassandra to receive medical treatment against her will." They argue further that Cassandra should have been designated a "mature minor" during the original Superior Court case and allowed to make her own decisions about her medical care. DCF rejected the mature minor argument and argued that it is their duty to act in cases like this—cases in which a child is likely to die if medical decisions are left up to the parents.

Ultimately, the Connecticut Supreme Court ruled that the state has the right to continue making medical decisions for Cassandra—at least until her 18th birthday in September.

Questions:

1. Under what conditions is it permissible for children/minors to refuse medical care?

2. Under what conditions is it permissible for parents to refuse medical care for a child?

3. Is the state justified in removing Cassandra from her home and forcing her to undergo chemotherapy? Under what conditions is the state justified in forcing a patient to undergo treatment against her will?

Resources:

Megan Thielking, "Why a 17-Year-Old With Cancer is Being Forced to Undergo Chemo Against Her Will," *Vox*, last updated on January 8, 2015, http://www.vox.com/2015/1/8/7513423/why-a-17-year-old-with-cancer-is-being-forced-to-undergo-chemo

"Medical Consent: Cassandra's Catch-22," *The Economist*, January 14, 2015, http://www.economist.com/blogs/democracyinamerica/2015/01/medical-consent

CASE 15
Clinical Trials for Ebola Virus Disease

The 2014 outbreak of Ebola Virus Disease (EVD) in West Africa was the largest on record with 21,373 reported cases, 13,477 laboratory-confirmed cases, and 8,468 deaths in Guinea, Liberia, and Sierra Leone.[3] There is overwhelming support for clinical research on new EVD treatments. Dr. Muñoz, a researcher working with the EVD-Free Foundation, has been tasked with designing a series of three clinical trials to test three experimental treatments—an experimental vaccine, a new antiviral drug, and the use of blood transfusions from EVD survivors. Designing an ethically acceptable trial is challenging, however, and the researchers at EVD-Free are divided into two factions.

The first faction argues that blinded randomized control trials give the researchers the best chance of finding an effective treatment for EVD. Single- and double-blind randomized trials have become the gold standard for clinical research. They are recognized as the most reliable and robust of clinical trials. In a blinded randomized trial, some patients will receive the experimental treatment and some patients will receive a placebo. Through randomization, the "design controls for effects (known and unknown) that may affect the results of other study designs".[4] Further, randomized trials "require a relatively smaller population"[5] and can therefore be completed more quickly—a significant consideration given the rate of infection.

The second faction argues that, given the high fatality rate among patients with EVD, blinded randomized control trials are unethical. We can only justify giving patients a placebo as part of randomized when clinical equipoise is satisfied. "Clinical equipoise is the assumption that there is no one 'better' intervention present… and is considered a necessary feature for clinical service practitioners to ethically enroll patients into clinical trials."[6] But, this faction argues, we do believe that the experimental treatments are better than the available alternatives. The group is lobbying EVD-Free to being with nonrandomized trials, "in which all eligible patients who want

[3] http://www.cdc.gov/vhf/ebola/outbreaks/2014-west-africa/case-counts.html last updated January 16, 2015.
[4] Lina Moses, "Don't Ignore Established Research Ethics When Treating Ebola", *The New York Times,* last updated on December 1, 2014, http://www.nytimes.com/roomfordebate/2014/12/01/experimental-drugs-and-the-ethics-of-fighting-ebola/dont-ignore-established-research-ethics-when-treating-ebola
[5] Lina Moses, "Don't Ignore Established Research Ethics When Treating Ebola", *The New York Times,* last updated on December 1, 2014, http://www.nytimes.com/roomfordebate/2014/12/01/experimental-drugs-and-the-ethics-of-fighting-ebola/dont-ignore-established-research-ethics-when-treating-ebola
[6] Chad Cook and Charles Sheets, "Clinical Equipoise and Personal Equipoise: two necessary ingredients for reducing bias in manual therapy trials", *The Journal of Manual and Manipulative Therapy,* February 2011, 19(1): 55-47.

the medication can have it"[7], on the grounds that nonrandomized trials could offer treatment to more people and minimize in-study deaths.

Dr. Muñoz must balance the goal of finding an effective treatment for EVD with the ethical constraints on human subjects' research. If she decides on the blinded randomized trials, then fewer patients will receive the experimental treatments, but the EVD epidemic may end sooner. If she decides on the nonrandomized trials, more patients will be helped, but it may take longer to find an effective treatment for EVD.

Questions

1. Should EVD-Free conduct the blinded randomized control trial even though it will mean that fewer patients are treated?

2. Should EVD-Free conduct nonrandomized trials, which will offer treatment to more patients immediately, but may result in a longer wait to find an effective treatment for EVD?

3. Are there socially relevant factors—for example, economic status, age, or race—that should be considered when deciding which trial method to pursue?

[7] Peter Hornby, "Nonrandomized Trials Could Minimize Deaths of Ebola in West Africa", *The New York Times,* last updated on December 2, 2014, http://www.nytimes.com/roomfordebate/2014/12/01/experimental-drugs-and-the-ethics-of-fighting-ebola/nonrandomized-trials-would-minimize-deaths-of-ebola-in-west-africa