2023 National Bioethics Bowl Case Packet

Northeastern University
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*This packet contains 12 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: A Danger to Oneself

Jane is an 18-year-old girl diagnosed at age seven with Anorexia Nervosa (AN). She is now completing her senior year in high school. Jane is a strong student who wishes to pursue a premedical degree in college. She exercises every day and tightly controls her caloric intake. She is being treated for her AN at a large medical center by the adolescent health department. At the time of her last visit, two months ago, Jane was significantly malnourished and had severe osteoporosis (BMI 16; height 156cm; Wt. 39kg.). Her last bone scan showed significant deterioration in her long bones and spine, leaving her at greater risk for fractures. She refuses any treatment or referrals for counseling, thinking she can manage her eating disorder "on her own."

At her last appointment, her providers informed her that she has dangerously worsening osteoporosis, and her heart function is a growing concern. Jane has had a good relationship with her adolescent medicine physician, who was able to convince her to continue to come to the hospital for monitoring of her bone health. Her physician holds out hope that she can influence Jane in the direction of treatment.

AN has the highest mortality of all psychiatric illnesses, with fatality rates ranging from 7- 14%. Jane has a disease characterized by denial of illness. This is the case even in the presence of high intellectual achievement. Her parents describe her as "thinner than ever." AN is not "cured," but managed, and compelled treatment may or may not work; there isn't definitive data proving one way or the other. What the data do show is that the earlier treatment is started, the more likely it is to be successful. While AN has the highest mortality rate of all psychiatric illnesses, it is difficult to predict when death will occur because some patients tolerate semi-starvation better than others.

The ethics consult service at the medical center has been called by adolescent medicine due to her refusing care. The medical team is worried about Jane's well-being, saying she could die at any time from complications related to her disease. Jane's parents would like the ethics consult team to make a recommendation that may be used in a legal proceeding to compel treatment. They have hired a lawyer to pursue power of attorney and a certification for commitment. The attorney met with Jane, and was unable to convince her to go willingly. A bid to declare her a danger to herself has not been possible because she refuses to see a psychiatrist.

The medical team seeks an ethics recommendation on what ethically permissible courses of action are available to them.

Questions:

1. Jane has just turned 18-years-old and is in the process of developing her autonomy. She has a scholarship to a four-year college, but still relies on her parents for financial and emotional support. Does her right to autonomy outweigh her family's, physician's, and society's obligation to care for her if she cannot act in her best interests? We allow drug addicts, who do not act in their own best interests to make their own decisions; is this any different? Does having just turned 18 make an ethical difference, even if not a legal one?
2. Compelling treatment might damage the already strained relationship Jane has with her adolescent medicine physician. Currently, Jane is willing to come to the hospital for bone scans several times per year. Does the chance of putting her on a path towards cure outweigh the risk of driving her away from all treatment?
3. Hospital counsel has advised the ethics consult service that should Jane invoke it, the hospital will no longer be allowed to give her parents information on her condition; doing so would violate HIPAA. Does the legal requirement of HIPAA outweigh the parent's right to know about their daughter's health, in that they 1) continue to support her financially, and 2) are fighting to save her life.

Case 2: Best Interests and Parental Authority

The pediatric palliative care (PPC) and the heart and kidney unit (HKU) teams are considering withdrawal of the artificial nutrition and hydration (ANH) being used to maintain Brenda, a 6-month-old female with complex cardiac disease, devastating neurological injury, and ongoing pain. Brenda's parents strenuously object.

Brenda is a 6-month-old female infant who has suffered diffuse neurological injury (8/10 severity) due to oxygen deprivation. Severe ischemia in all 4 limbs that has resulted in loss of both hands and both feet. Two significant iatrogenic factors contributed to Brenda's current condition. The first is severe neurologic injury secondary to ECMO (extracorporeal membrane oxygenation) decannulation and subsequent cardiac arrest. This damage is diffused throughout the brain. Her ability to suck and swallow is doubted by her physicians, but unknown. The second is severe ischemia to all of her limbs following prolonged ECMO (related to inability to remove Brenda from bypass following surgery). Her hands and feet are reportedly not salvageable, but remain attached to advancing necrotized live tissue, forming transition zones on all four limbs.

The MRis presented during the consult display extensive brain tissue loss throughout prefrontal and midbrain areas, leaving only the brainstem intact. The patient requires medication to prevent seizures, is blind, will likely be unable to exhibit motor control functions such as sitting, and has a high chance of being non-verbal. She may be able to hear.

Brenda's parents believe no one can decide to "call her back to heaven" except God. They visit her daily, and are joined periodically by members of their church. Multiple family meetings have occurred in which the medical team attempts to convey the severity of Brenda's condition. At the last family meeting the discussion became heated and the parents finally said, "As long as she has a heartbeat, that is enough for us."

Nurses are asking to be reassigned in increasing numbers due to moral distress. Most think providing this care is wrong when there is no chance of benefit, but some support the parent's right to decide, and are uncomfortable with withdrawal of ANH. The PPC and HKU attending physicians believe withdrawing ANH and redirecting the goals of care to palliation (comfort care) is the ethical course of action. They point out that as the body shuts down, food and liquids can be uncomfortable to ingest; Brenda will not "starve," but rather her death will be peaceful and her suffering will end.

Unlike specific neurological injury, where other, undamaged regions of the brain can "take over" certain functionality, diffuse brain damage has no such remedy. While traumatic brain injuries can improve over time, anoxic brain damage does not. Brenda, while not meeting the criteria for brain death, will be unable to interact with the world in any meaningful way. As reported by Neurology, Brenda will never be able to develop the capacity for thought, or move intentionally, and is likely to be both nonverbal and unable to maintain her body positioning.

However, Brenda is capable of feeling pain, and the transition zones between live and necrotic tissue on all four limbs cause her significant pain and suffering. She is facing probable 4-limb debridement/amputation. The transition zones are being monitored, but daily wound care causes significant pain. Debridement of necrotized tissue on all four limbs will eventually be needed if efforts are made to preserve limb length. Wound care reports undetermined lengths of healthy tissue exist towards the centers of each limb. Artificial life-support could maintain her for an indefinite period of time-months to years.

Questions:

I. The medical teams have asked for an ethics recommendation. How do you weigh the two competing moral claims: parental authority to make decisions on behalf of their minor children, and the physician's fiduciary duty to act in the best interests of her patient?
2. If the hospital administration stands behind the physicians, and the family were to go to the media, the negative publicity could deleteriously affect the hospital's fundraising ability, which the nonprofit uses to provide free medical care to those who cannot afford it. Should the administration choose to support ending Brenda's suffering without any portent of benefit at the risk of this potential damage to their mission to provide care to large numbers of children?
3. What is in Brenda's best interests? Can death ever be said to be in one's best interests?

Case 3: Captive Retirement

In 2015 the United States National Institutes of Health (NIH) stopped funding virtually all biomedical testing on chimpanzees, effectively ending government funded experimentation on this species of great apes in America.[1] In the United States, much of the chimpanzee research involved giving the primates cancer, HIV and hepatitis, in an effort to advance therapies and cures; however, after years of research, the work was not proving fruitful. On top of that, many animal welfare and animal rights groups were voicing outrage over our closest genetic relatives enduring this form of captivity and experimentation, when only a small number of countries other than the U.S. continued biomedical research on chimpanzees. Currently, about half of the NIH laboratory chimpanzees still remain in captivity, while the rest have been moved to sanctuaries or, in some cases, zoos.

In 1993, Philosophers Peter Singer and Paola Cavalieri helped form an international organization of ethicists and scientists called the Great Ape Project, which sought to extend legal rights to all great apes.[2] Similarly, attorney and animal rights activist Steven Wise, began suing on behalf of chimps in captivity for research and entertainment, arguing that animals with certain levels of 'cognitive complexity' (apes, elephants, dolphins and cetaceans) should be recognized as 'legal persons' rather than 'legal things'. Wise, famed primatologist Jane Goodall, and other activists helped form the Nonhuman Rights Project (NhRP) which argues that cognitively complex animals should have 'personhood' and should have basic legal rights.[2] Wise argues that these animals have autonomy, a theory of mind, and they should have 'dignity rights' — the right to not be killed, tortured, or imprisoned. Britain banned research on chimpanzees, orangutans and gorillas in the late 1990s, and New Zealand gave legal protection from experimentation to apes in 2000. Spanish Parliament approved 'human rights' for chimps in 2008.[4] In 2010, the European Union banned all ape experimentation and certain forms of entertainment.

However, the retired chimps of American biomedical research could, of course, not be released into the wild, as most of them had never set foot outside of the lab, and many of them had special physical and psychological needs. According to ChimpCare, in 2017 there were still around 547 chimps that were living in captivity inside research facilities in America.[5] Chimp Haven and Project Chimps are the two primary havens for these

retired chimps, but they do not have enough employees or funding for all retired U.S. research chimps.

Some chimps still held in captivity have been evaluated as too ill to risk being moved to a sanctuary. Housing these chimps in laboratories still costs tax-payer's money. In 2019, the New York Times reported that all 44 chimps still held at a Lab in New Mexico were judged to be too ill to move to Chimp Haven — a private non-profit sanctuary that cares for over 200 chimps from retired NIH projects.[6] Philosopher Dr. Lori Gruen argued that Chimp Haven has cared for chimps with the same ailments described by the New Mexico vets, and other activists are calling for the ill chimps' health to be reviewed again, hoping they could be moved to sanctuaries.[6] Currently, workers at Chimp Haven are given vasectomies to the males, and eventually plan to shut the sanctuaries down when all of the retired chimps pass away. However, some private companies have given their retired research chimps to non-AZA accredited zoos, sparking more controversies and backlash from animal welfare groups.

Questions:

1. What moral responsibility, if any, does the United States have in making sure these retired research chimps are moved to sanctuaries?
2. Do you think biomedical research should be banned on animals that display a certain level of 'cognitive complexity'?
3. If the research on chimpanzees had yielded more positive results and potential benefits for humans, would it have been ethical to continue the experimentation on them?

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5 https://www.nytimes.com/2017/11/07/science/chimps-sanctuaries-research.html

6 https://www.nytimes.com/2019/10/24/science/chimps-retire-sanctuary.html
https://www.nonhumanrights.org/unlocking-the-cage/

Case 4: Is Medical Crowdfunding Ethical?

We have all seen the appeals on social media: a cute child, often white, with special medical needs, for whom her impoverished parents cannot pay for the needed medical care. A link is provided to a "Go Fund Me" or similar account and, with a click of a button, a credit card is invoiced, the patron feels like a savior and the problem moves toward a solution.

All true and good? Maybe not. Although medical crowdfunding is increasingly used by the 32 million Americans who lack medical insurance, it does not always succeed.

Consider that an illiterate, uninsured family of color with a child with cerebral palsy may lack the knowledge and resources to create a "Go Fund Me" account for their child, whereas a similar child of a white, suburban family may have an account created for him to cover costs not typically covered by medical insurance.

More generally, do crowdfunding appeals to pay for medical needs divert attention from structural inequalities in America? If one person's medical care is covered, what about the other 32 million?

Effective altruism has criticized "feelgood, checkbook" giving, which makes the giver feel good but which, according to empirical studies in the real world, does little good. Is medical crowdfunding an example of "feelgood" giving with unchecked results?

Bioethicists have criticized the "rule of rescue," where an identified patient, often cute and socially connected to the staff, gets not just one scarce medical resource (such as a liver transplant), but many more (if the first transplant fails, the identified patient gets another liver, even though others never got a first transplanted liver.

Would it be better to give the intended money to groups that advocate and lobby for universal medical coverage in America? Does medical crowdfunding actually hurt such efforts, by applying band-aids to publicized cases and by relieving public pressure to improve the system?

Philosopher Alisha Liberman calls this "the duct tape problem," where there is a serious structural injustice affecting many citizens but also where a short-term solution is available. Yet focusing only on the structural problem may leave needy people in the lurch in the present.

Moreover, are there immoral and moral platforms for medical crowdfunding? Do the most popular appeals get too much money, and the unpopular ones get little? Should such information be available to potential donors? Is it ok that appeals for medical care for transgender adults do not get as much money as do appeals to help abandoned, HIV+ babies?

Questions:

1. Is medical crowdfunding merely a stopgap measure in an unjust medical system in America?
2. How could medical crowdfunding be made more ethical?
3. Is it possible that donors could argue both for structural change and contribute to specific crowdfunding cases that meet certain criteria?

References:

Liberman, Alida, "A Framework for More Ethical Medical Crowdfunding/' presentation at the Pacific Meetings of the American Philosophical Association, Vancouver, Canada, April 2022 (See draft of her paper appended to last case).

"Rule of Rescue," https://en.wikipedia.org/wiki/Rule_of_Rescueliver

Barcelos, Chris, "Go Fund Inequality: The Politics of Funding Transgender Medical Care," *Critical Public Health,* 30:3, 330-339.

Kenworthy, Nora, "Like a Grinding Stone: How Crowdfunding Platforms Create Responsiveness: A Reply to Larry Temkin," *Journal of Practical Ethics,* 7:1: 40-48.

Moore, Bryanna, "Medical Crowdfunding and the Virtuous Donor," *Bioethics,* 33: 238-244.

Snyder, Jeremy, " Crowdfunding for Medical Care: Ethical Issues in Emerging Health Care Funding Practice," *Hastings Center Report,* 46 (6): 36-42.

Case 5: China's DNA Surveillance

On December 3, 2019, Yves Moreau, a biologist and writer for Nature published an essay - "Crackdown on Genomic Surveillance" - calling for intervention on the Chinese government's practices of buying DNA-profiling technology and using it to perform human-rights abuses. It states that China's police are using a national DNA database along with cameras and facial scanners to monitor the minority Uyghur Muslim population in China's western province, Xinjiang. Moreau noted that US, UK, and EU-based companies are the largest suppliers of DNA- surveillance technologies. He also specifically called out Thermo Fischer Scientific, a company based in Massachusetts, for selling products to and working with the Chinese Ministry of Justice and the People's Public Security University of China in their initiatives to surveil the Uyghurs and to "build a population-scale database for DNA, fingerprint, face and voice information in a major Chinese city." The company did eventually end their relationship with China after two years of public outrage and political pressure. A lobbyist for Thermo Fisher responded to Moreau's article arguing that that universal DNA databases are "inevitable" and the only thing stopping them from being implemented in western countries are public parliamentary processes and the influences of protests. Moreau warns that "the use of DNA for state-level surveillance could become the norm in many countries."

Moreau calls for updated legislature on identification processes, citing the fact that legislation has passed for fingerprint sensors, but no for the more advanced and invasive facial and DNA recognition technologies. Moreau studied 529 articles, including 40 published by three leading forensic journals, and found that Uyghurs and Tibetans were 30 to 40 times more frequently studied than the Han majority[1] in China, relative to population size.[2] Previous reports, including one by the New York Times in April of 2019, had stated that China's use of facial recognition to monitor the Uyghurs was the first known time a government had intentionally used artificial intelligence for racial profiling. The expanding network of Chinese cameras is integrated with facial recognition capabilities exclusively for Uyghurs and keeps track of their activity for review. Technology had previously been used to monitor the Xinjiang province which most Uyghurs reside in, but it is being expanded to monitor the wealthier Uyghurs in coastal eastern cities.[3]

Another Time's article details Tahir Imin's experience as a Uyghur in a Beijing airport, where he is brought aside for a 'free health check', one where his face is scanned, blood is taken, and his voice is recorded, but his heart is not checked and his weight not taken. The Chinese government *is* forcing Uyghurs into 're-education' camps, and this racial profiling will be used to track down any Uyghurs who resist.

Genetic material was provided by Kenneth Kidd, a prominent geneticist at Yale University, and technology would be used from the aforementioned Thermo Fisher Scientific. Although Kidd willingly gave these samples to the Chinese government, he claims to be unaware of its intended use. The Chinese government has taken advantage of the public database of genetic information, much of it from the United States, and in turn, they have provided the database with Uyghur DNA. The global scientific community is under scrutiny for allowing this exchange to occur, and many researchers from top universities are calling for this initiative to be closed off from the Chinese government.[4]

On Tuesday, December 3, 2019, the US House of Representatives voted nearly unanimously on a bill condemning China's treatment of ethnic minorities. Many scientists have expressed their worry that the DNA research, in particular, violates the worldwide scientific rules regarding consent. It is nearly impossible for scientists to guarantee that the Uyghurs involved in this study gave their blood samples willingly.[5]

Questions:

1. What steps are researchers morally obligated to take (if any) to make sure their research in this area can't be used for the purpose of government surveillance?
2. What uses of DNA research should be considered morally acceptable?
3. Are private corporations morally obligated to take steps to make sure their products can't be used in ways they would find morally unacceptable?

[1] Scientific reports, Nature, Springer Nature Limited "Genetic diversities and phylogenetic analyses of three Chinese main ethnic groups in southwest China: A Y-Chromosomal STR study' October 18, 20ll8.

[2] Nature, Springer Nature Limited "Crack down on genomic surveillance" December 3, 2019.

[3] Paul Mozur, "One Month, 500,000 Face Scans: How China is Using A.I to Profile a Minority" *The New York Times,* April 14, 2019.

[4] Sui-Lee Wee, "China Uses DNA to Track Its People, With the Help of American Expertise", *The New York* Times, February 21, 2019.

[5] Sui-Lee Wee and Paul Mozur, "China's Genetic Research on Ethnic Minorities Sets Off Science Backlash", *The New York Times,* December 4, 2019.

Case 6: Barring Disabled Immigrants to Control Costs

Despite offering all their citizens national medical care, both New Zealand and Australia enforce policies banning potential citizens from immigrating who might be costly for their medical systems.

Consider 8-year old, Shaffan Muhammad Ghulam, a child of Pakistani immigrants who was born in Perth, Australia, who has a rare genetic condition that paralyzed him and forces him to use a ventilator at night to breathe. For seven years, his family has fought to keep him in Australia and to keep his medical care covered by Australian medicine, but Australia has been trying to deport the family because his treatment is deemed too costly for its medical system.

The biologist-philosopher Garrett Hardin famously wrote of the "tragedy of the commons" and "lifeboat earth," where he argued that nations and communities that do not restrict access to their public goods are doomed to die.

One of the primary duties of a just society at the local, state, national, and international levels is to define and manage public goods. But what is the best policy of a just society for those on its borders who wish to join it? Should it take in only the most talented and most healthy, or should its borders be open to all?

Canada and the European Union passed laws requiring medical systems to cover medical care for migrants with disabilities.

Decades ago in the United States, stories appeared in newspapers about pregnant women carrying fetuses with disabilities from Mexico and South America who struggled to make it across the border to give birth, such that their children would be American citizens and entitled to medical care in the USA. In South America, the Zika virus left thousands of babies with microcephaly, a condition that in the USA would require lifetime care of 1 million dollars. Should immigrant mothers with Zika babies be barred from crossing our borders?

Denial of care to disabled children may result in an entire family losing its visa, as is the case in Australia. In New Zealand, the family may stay, but not the disabled individual.

When publicized, New Zealand's Prime Minister, Jacinda Ardem justified her nation's policy because her medical system is "fragile." She noted that once permanent visas are granted, all medical care to New Zealanders is free.

New Zealand also denies visas to children with intellectual disabilities who require

special care. Families may appeal denial of visas, but the process may take many years and leaves the parents in limbo.

Questions:

1. When a country has a national system of medical care which covers all the residents in it (citizen and not), is it morally permissible for their immigration regulations, laws, etc. to consider the medical costs of potential immigrants in deciding whether to let them in?

2. Do host countries have a moral obligation to provide medical care to the immigrants residing in their country?

3. When a country's ability to provide a form of medical care is scarce and it cannot provide such medical care to all, does that country have a special moral obligation to prioritize the allocation of such medical care to its own citizens over non-citizens?

References:

1. Natasha Frost, "If Migrants are Disabled, 2 Nations May Bar Them, Based on Costs of Care," *New York Times,* October 31, 2022, p. AS.

2. "Immigrants' Access to Health Care in Texas: An Updated Landscape," https://everytexan.org/images/HW_2016_ImmigrantsAccess_FullReport.pdf

3. "Tragedy of the Commons,' https://en.wikipedia.org/wiki/Tragedy_of_the_commons

4. "!Disabmty & hrnmignntion L nv ira t!hc United State§ of Amcricat Coimd! of Canadians with DbabiiWes, **http://www.ccdonline.ca/en/socialpolicy/access-inclusion/disability-aod-immigration-law-in-usa**

Case 7: The Right to Die: Should Medical Assistance in Dying Apply to Patients with Mental Illness?

In June 2016 Canada's Parliament passed federal legislation that allows eligible Canadian adults to request medical assistance in dying in cases of terminal illness, a law implemented after many years of resistance. Four years later, the Minister of Justice and Attorney General of Canada introduced Bill C-7 in Parliament, which removed the stipulation that Canadians must have a "reasonably foreseeable death" to be eligible for medical assistance in dying, expanding access to those living with disabilities and chronic illness.

People still must apply and be deemed eligible by two clinicians who must determine whether the patient has an irremediable condition that causes them intolerable suffering and whether they have capacity — whether they understand their condition and their decision and its consequences. While there is an initial two-year mental illness exclusion such that patients who are solely suffering from mental illness cannot access MAID, this exclusionary period ends on March 17, 2023. During this two-year waiting period, an expert panel has been convened to advise on the safeguards to protect people with mental illnesses from exploitation or harm.[1]

Reactions to Bill C-7 have been strong and varied. According to bioethicist Anna Vargo, "Without eliminating stigma, including [MAID] access for individuals with mental illnesses and disabilities may increase the perceived pressure of being a 'burden' to society. This dangerous cascade could indirectly imply to these vulnerable individuals that their lives are not worth living—encouraging them to end their lives prematurely."[2] Defenders of the Bill object to patemalistically treating those with mental illness as being exceptionally vulnerable persons. In their view, capable individuals who are mentally competent but suffering from chronic mental illness — and who find the prospects of going on with life in this condition unbearable — should be equally afforded the right to die: As some claim, "It is unjustifiable to exclude psychiatric patients from benefiting from a medical intervention that is designed to preserve autonomy and reduce suffering, without giving due consideration to individual variability."[3]

Still other commentators claim that MAID is not a medical act in the context of mental illness.

John Maher, psychiatrist and editor-in-chief of the *Journal of Ethics in Mental Health* writes:

> It concerns me that MAID for persons experiencing mental illness is claimed to be a shared medical decision and a subsequent medical act by a physician with a mentally ill patient. "Assistance" (the "A" in MAID) is an ambiguous term, but if it is a euphemism for "helping kill" the patient, then there is nothing in the long history of medical ethics and values that would construe that as a "medical act." If I am a doctor and help someone commit suicide, my involvement has not thereby made the suicide a "medical act". Many other non-physicians can proffer similar assistance.[4]

Canadians with physical and mental disabilities are often the worst-off, poor, and lack housing, social support, and access to medical treatment, so critics of MAID worry that such citizens wills succumb to MAID. Two recent cases support those fears. In February 2022, a 51-year- old woman with multiple chemical sensitivity syndrome (MCS) was granted MAID after her chronic condition became intolerable and her disability stipend left her little to survive on. Unable to find assistance in securing suitable housing, the woman chose death instead, claiming in a video that "The government sees me as expendable trash, a complainer, useless and a pain in the ass." In April 2022 a 31-year-old woman, Denise — also with a diagnosis of MCS — applied for MAID after unsuccessful attempts to locate housing with reduced chemical and smoke exposure that she can also afford on her disability benefits. According to Denise, it was easier to apply for MAID than it was to find suitable housing; as she put it, "I've applied for MAID essentially...because of abject poverty,"[5] Her MAID application was put on hold, however, after a GoFundMe fundraiser garnered $65,000 from 1,000 donors. But because Denise still suffers from painful chronic health problems that she claims haven't been properly handled, she hasn't canceled her MAID application

Supporters of Bill C-7 see things differently. They claim that such cases are being used by groups opposed to MAID to delay its expansion, rather than looking at how governments can improve the lives of people with disabilities. Chantal Perrot, a Canadian doctor and MAID provider, claims that "Inadequate housing is not one of the eligibility criteria for medical assistance in dying. While somebody's living circumstances may contribute to their suffering, it does not constitute the grievous and irremediable medical condition, which must exist."

Jocelyn Downie, a Canadian law professor and expert in end-of-life policy, claims that despite the media attention surrounding these cases, there are extensive measures within the system to protect Canadians: "You have to meet rigorous eligibility criteria. And being poor and not having a home, or a home that is suitable for you, does not make you eligible."[6]

Questions:

1. Is the Canadian government morally justified in extending medical aid in dying to persons with mental illness? Does doing so justifiably uphold the rights of the mentally ill to choose death in certain cases or does it violate equal respect and protections for people with disabilities?

2. Should it be a criterion for MAJD that a patient must have a ""reasonably foreseeable death" in order to be eligible for medical assistance in dying? Why or why not?

3. Is assisting in killing people with mental illness a legitimate application of medical assistance in dying? Or is it rather helping people to commit suicide, something that they could do without medical involvement?

[1] At the time of writing this case Justice Minister David Lametti announced the federal government will be negotiating an "extension" to the deadline. Some parties have expressed concern that the appropriate safeguards to protect people suffering from mental disorders would not be in place by the end of the sunset clause on March 17 2023. Lametti has expressed confidence that they could be ready by that date, but he claims they want to take the time to "get this right" (https://nationalpost.com/news/politics/maid-expausion-delay-lametti)

[2] https://journals.librruy.columbia.edu/index.php/bioethics/article/view/9473

[3] https://pubrned.ncbi.nlm.nih.gov/29635929/

[4] MaherJ. "What troubles me as a psychiatrist about the physician assisted suicide debate in Canada." *J Ethics Mental Health.* 2017;10.http://www.jemh.ca/issues/v9/documents/JEMH£ina1-Editorial-iii.pdf

[5] https://www.ctvnews.ca/health/woman-with-disabilities-nears-medically-assisted-death-after-futile-bid-for-affordable-housing-1.5882202

[6] https://www.theguardian.com/world/2022/may/11/canada-cases-right-to-die-laws

Case 8: Organizational Ethics in the Emergency Department

Susan is a 67-year-old woman suffering from advanced metastatic breast cancer. She was diagnosed with cancer seven years ago. She is a health-conscious person, and the cancer was detected early and treated aggressively with surgical tumor removal followed by adjuvant chemotherapy. Due to early detection and aggressive intervention, Susan was able to battle her cancer into remission. Having fought through many months of fatigue, nausea, cramping, vomiting, and pain, Susan worked hard to improve her health. She felt things were looking up, but 18 months later, the cancer returned. Susan elected to fight it aggressively again, maintaining her positive attitude. Her tumors were more aggressive, but repeated rounds of chemotherapy and radiation sent the cancer into remission once again.

That was four years ago, and since that time, Susan's immune system has remained compromised. She suffered other lasting effects of aggressive cancer treatment, as well. For example, peripheral neuropathy has caused her constant pain that is only partially managed by strong opioid therapies, which themselves induce fatigue, nausea, and constipation. The neuropathy makes walking difficult, and Susan is exhausted by the smallest exertions. She has worked diligently to rebuild her health, always more upbeat than it would seem possible for someone who suffers as she does.

Two years ago, the cancer returned. Despite all attempts at treatment, it has become much more virulent. It has metastasized and spread into Susan's liver, lungs and lymph nodes. Susan's oncologist indicates that while the five-year survival rate for stage 4 breast cancer is approximately 20-25 percent, Susan has no realistic chance of either another remission, or surviving to the five- year mark. Even if she did, her chronic pain, neuropathy, and fatigue would continue to worsen; she will likely become bed bound as the cancer spreads to her bones.

During her initial fight with cancer seven years ago, Susan discussed the matter with her husband and made a living will specifying that she does not want aggressive life-sustaining treatment if there is no possibility of, if not cure, at least remission. All her life, Susan exercised, ate well, and enjoyed being physical-spending time outside in her garden, hiking, and traveling. With the onset of the neuropathy and chronic pain (following her first relapse), she could no longer do those things. Having lived with that for four years, she gathered her family together and explained that while she loved her life and her family, she

had lost many of the things that made life enjoyable, and the progressive loss of function and debilitating pain degraded her quality of life further still. Her family agreed to support her decision to complete a MOLST form (Massachusetts Medical Orders for Life-Sustaining Treatment) which made explicit her desire not to be either resuscitated or kept alive using artificial means of life support. The MOLST form was completed and signed by her physician. Susan's family honored her wishes by ensuring her oncologist had made the form part of her electronic medical record and posted a copy on her kitchen bulletin board should EMTs be called to her home.

Susan has just been brought to the emergency department following a suicide attempt. Her living will states that she refuses both CPR and artificial life-sustaining treatment. However, Massachusetts law requires physicians to attempt to revive patients who have attempted suicide, since many suffer from mental health problems that once treated, relieve their desire to end their lives. But, Susan is known to the hospital staff. She does not have any mental health problems, and has been suffering terribly from a fatal disease. Unwanted medical care constitutes battery. Consent to medical treatment for competent adults is a foundational principle of biomedical ethics. However, suicide has been called "a permanent solution to a temporary problem," and the state has an interest in protecting the lives of those with mental illness who attempt to take their own lives.

Questions:

1. As the clinical ethicist on call when Susan is brought to the emergency department, you are asked by the attending physician whether or not the MOLST form should be honored in light of this being a suicide attempt.
2. Is this issue most appropriately handled by the clinical ethicist, or the risk manager?
3. If the risk manager states that Susan must be revived and aggressive life-sustaining measures used, do you alter your ethics case note to support the decision?

Case 9: Ultra-Personalized Medicine

The New England Journal of Medicine has identified the first known custom treatment for a disease of genetic origin. The drug is called Milasen, and it is named for a young girl named Mila Makovec. Mila has a condition called Batten's disease, a rapidly progressing and fatal neurological disease that is recessive, meaning both of her parents must give her the mutated gene for the disease. Upon inspection of her genetic code, researchers found that Mila only had one mutated gene, and the other gene was located on an extraneous piece of DNA, leading to the scrambling of an important protein. Dr. Timothy Yu of Boston Children's Hospital proposed that a custom piece of RNA could block the effects of the extraneous DNA, however, this drug would be extremely costly. Mila's mother used money from her foundation along with $3 million from a GoFundMe campaign to pay for the drug, which was cleared by the FDA and given to Mila via spinal tap starting in January of 2018. Mila may be too old to fully recover from Batten's disease, but her mother says she hopes that personalized medicine might help any younger children with a rare disease. Personalized medicines for rare genetic diseases are very new, in fact of the over 7 thousand known rare diseases (below 1 in 2 million[37]), less than 1 0 percent have an F.D.A.-approved treatment. Milasen is a new step forward in personalized medicine, deemed ultra- personalized medicine, because it is designed for a single patient.

The only other instance of medicine being personalized for a single patient is CAR-T cancer therapy, although these therapies are not drugs like Milasen.[38] CAR-T therapy is one of the forefronts of immunotherapy. CAR-T cell therapy has primarily been used in clinical trials for patients with advanced blood cancers. It has been deemed a "living drug" because the therapies rely on T-cells to orchestrate an immune response to the pathogenic cancer cells. T-cells must be drawn from each individual patient and genetically engineered with receptors to target an antigen on the tumor cells. CAR-T treatments, until recently, were seen as 'boutique therapy' by researchers because of their high cost and small, defined patient groups. However, the CAR-T therapy field has grown quite a lot in the past 5 years has brought a new enthusiasm about the treatment. However, the cost is still an issue, with a single treatment costing as much as $375,000 and Medicare only covering costs in FDA-evaluated healthcare facilities.[39] The next step forward in CAR-T therapy is

de-individualizing care by creating off-the-shelf therapies derived from healthy donors.[40]

Ultra-personalized, or precision, medicine is said to be the next frontier in medicine. We are presently in the era of pharmacogenomics, creating drugs based on clinical outcomes and patient responses to drugs.[41] In the future, medicine will not be tailored from a group of people and then given to the masses, instead medicine will be personalized for each person, taking into account everything from their lifestyle to their genome.[42]

While precision medicine may be the way of the future, in the era of pharmacogenomics the individual research is costly and time-consuming. With this new frontier, the job of the clinician conflicts with the job of the clinical researcher. The clinician's goal is to maximize an individual patient's health, but a clinical researcher's goal is to produce research that is useful to all of society. The healthcare industry, a large as it is, is truthfully overwhelmed when it comes to the amount of resources available. With limited resources, as of now, it is impossible to make custom drugs available to everyone. Is it ethical to ask a clinical researcher, who is meant to work to benefit the common good over the individual, to dedicate scarce resources to benefit the individual over the common good? Wealth inequality is also a factor, with custom drugs only being financially attainable by the rich elite, in Mila's case her mother's successful foundation. The FDA must also answer the question of how it is going to clear drugs for personal use if the only person they can use for clinical trials is the patient the drug is designed for.[43]

Questions:

1. Is it morally justified use of clinical researchers' time to devote their time to ultra- personalized drugs?
2. Is it just that only the very wealthy will have access to ultra-personalized medicine?
3. Should the FDA revise its clinical rules to suit ultra-personalized medicine?

[39] **John Commins, "Medicare to Cover Costly CAR T-Cell Cancer Therapy Nationwide"** ***HealthLeaders,*** **August 8, 2019.** https://www.hea1thlead rsmedia.com/clinical-care/medicare-cover-costly-car-t-ceJl-**cancer-therapy- nationwide**

[40] **National Cancer Institute, "CART Cells: Engineering Patients' Immune Cells to Treat Their Cancers" July 30, 2019.** https://www.cancer.gov/about-cancer/treatment/research/ca:r-t-ce Us

[41] **Jill Adams, "Pharmacogenomics and Personalized Medicine"** ***Nature Education,*** **2008.** https://www.nature.com/scitable/topicpage/pharmacogenomics-and-personalized-medicine-643/

[42] **Gameiro et. al, "Precision Medicine: Changing the way we think about healthcare"** ***Clinics (Sao Paulo).*** **November 23, 2018.** https://www.ncbi.nlm.nib.£rev/pmc/articles/PMC6251254/

[43] **Sarah Alawi, "The Ethical Conundrums of Ultra-personalized Drugs"** ***Harvard Law Bill of Health,*** **October 16, 2019.** https://blog.petrieflom.law.harvard.edu/2019/10/16/the-ethical-conund.rums-of-ultra-personal ized-drugs/

Case 10: Savior Sibling

In the early 1990s, Molly Nash was born with Fanconi anemia, a rare disease that results in the decreased production of blood cells.[44] Only a toddler, her bone marrow started to fail. When a bone marrow donor couldn't be found, it seemed hope was lost. That is, until Dr. John Wagner, director of the Division of Hematology-Oncology and Blood and Marrow Transplantation at the University of Minnesota, stepped in. Using a procedure that increases egg production, embryos could be genetically diagnosed before implantation and then born as an ideal match through in vitro fertilization (IVF). Lisa and Josh Nash, Molly's parents, decided to have a baby that was selected to match Molly's bone marrow perfectly. Lisa conceived a son, Adam, and immediately after his birth, doctors used the blood of the umbilical cord to give Molly a life-saving transfusion.

Most parents are willing to do anything to keep their child safe: "It was my baby and you know what, I was going to take care of her no matter what she had," Lisa Nash once said.[45] The benefits of preimplantation genetic diagnosis (PGD) can be very high. Parents can screen for known genetic diseases or conditions, preventing unhealthy embryos from being implanted.[46] This can decrease the risk of having a child who will inherit a disease from a parent. And, as in the Nash's case, it can be used to screen for genetic matches. However, this procedure does not come without risks. Using IVF-PGD, there is only a 54% delivery rate. Further, tests cannot check for every type of disorder and disease; it does not guarantee that a healthy child will be born. Finally, there is always the risk of false negatives.

The Nash's case is highly controversial, and there are others like it. Starting in the 90's, cases like theirs have been subjected to much media attention. It even inspired the popular book-turned- movie "My Sister's Keeper" by Jodi Picoult. Some opponents argue that the procedure is a slippery slope toward "designer babies," where parents screen for traits such as athletic ability, skin, eye, hair color, height, or intelligence to create the so-called perfect child. There is also a fear of having children not only to collect bone marrow, but to harvest organs

Other opponents argue that having a child intended to save a sibling places an undue burden on the new child. The thought that one was brought into the world to provide bone marrow, an organ, or blood for a sick sibling may be a difficult existential weight. The child must live with the fact that they are alive to save a sibling.

At the end of the day, what really matters is that the child is loved and cared for. Dr. Paul Billings, a board member of the Council for Responsible Genetics, said: "On the one hand this could theoretically commodify children, but on the other hand there is no evidence that children conceived this way are loved any less. As long as this family loves the child, then we should stay out of their business."[47]

Questions:

1. Is it morally permissible to have a child to save the life of another? Should doctors offer this option to parents? Why or why not?
2. At what point should the line between parental power and bodily autonomy be drawn? Should parents be able to make the decision for a child to give away biological parts of themselves, even before they are capable of understanding what that means? Explain.
3. Under what conditions, if any, is it ethical to screen embryos for specific traits? Which traits are deemed permissible?

Refererences:

4. [44] Save a Dying Child: Have Another One." *ABC News,* ABC News Network, 6 Nov. 2007, www .abcnews.go.com/W /Health/story?id=3826596&pne.e= l.
5. [45] Hendrickson, Molly. "CO Family Reflects on Decision to Save Daughter." *KMGH,* 14 Nov. 2017, w.-vw.thedenvercha1111el.com/news/locnl-news/l7-years-later-nash-family-opens-up-about-controversial-decision-to- save-d ing-daughter.
6. [46] PGD Benefits & Risks: Denver: Colorado Fertility Specialists." *University of Colorado Advanced Reproductive Medicine,* www.arm.coloradowomenshealth.com/services/ivf/pgd/risks.

Case 11: Three-Person Babies

On April 9, 2019, Greek doctors were able to successfully use a controversial method of in vitro fertilization (IVF) which allowed a woman to give birth to a healthy baby boy. What made this particular instance of IVF so remarkable was that the baby boy carried the DNA of three people.

The 32-year-old Greek mother had tried, unsuccessfully, to have a baby through IVF several times before. The new technique was developed for women for whom IVF did not work and for women concerned about passing on mitochondrial genetic diseases to their children. This technique, known as the 'spindle transfer,'[48] involves taking the sperm of a man and the genetic material of the mother but also removing the mother's unhealthy mitochondria (which has its own unique DNA). Then the mother's mitochondrial DNA is replaced with a healthy donor's mitochondria. Thus, this new method of lVF results in a child with three three people's DNA- the mother's DNA, the father's DNA, and the mitochondrial DNA of a donor. The mitochondrial donation is small, relative to the genetic material provided by the sperm and the egg, but nevertheless, this form of IVF results in a human who possesses the DNA of three unique individuals (although only two people's phenotypes).

Some critics of the spindle method, however, feel that the technique should be banned for infertility cases and only used when genetic diseases are trying to be prevented. These critics feel that their has not been enough research done on the potential health risks to the child.[49] Despite the controversy, the Greek doctors working on the project say that there are 24 other women taking part in the trial and eight embryos ready to be implanted.

2018 also marked another breakthrough for IVF. In October of 2018, a lesbian couple residing in Texas, Ashleigh and Bliss Coulter, made history by giving birth to a baby where one partner carried the child in the first stages of embryonic development and then the egg was later transferred to the other partner who eventually carried the child to term.[50] Samantha Allen of *The Daily Beast* writes, "In this case, Bliss was the "egg source," meaning that the eggs were harvested from her and inseminated using donor sperm. But then... rather than incubating the eggs outside of the body, Bliss "carried the embryo development for five days" inside her vagina using a small

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[4g] https://www.cnn.com/2019/04/11/health/birth-experimental-ivf-greece-scln-intl/index.html

[49] https://www.theguardian.com/science/2019/apr/l l/baby-wilh-dna-from-three-people--bom-in-greece-ivf

[50] httj)s://www.thedailybeast.com/these-lesbians-just-made-history-by-both-carrying-their-baby

medical device called an INVOcell capsule."[51] This form of lVF *is* actually less expensive than the 'traditional' method.

Questions:

1. Morally speaking, is donating DNA any different than donating blood, organs, or tissue, or do you think there is a morally significant difference? If so, why? If not, why not?
2. If the spindle transfer provided a gay or lesbian couple the opportunity to have offspring with both partners' DNA (although one of the partners would only be contributing mitochondrial DNA) would this be ethical, or should this method should be reserved to prevent genetic diseases?
3. Do you view any of the new fonns ofIVF described in the case as unethical? What are the potential benefits and problems you foresee for these methods described in the case?

References:

[48] https://www.cnn.com/2019/04/11/health/birth-experimental-ivf-greece-scln-intI/index.html

[49] https://www.theguardian.com/science/2019/apr/11/baby-with-dna-from-three-people-bom-in-greece-ivf

[50] https://www.thedailybeast.com/these-lesbians-just-made-history-by-both-carrying-their-baby