

CASE STUDIES FOR EXAM 2

The following case studies are taken from the *Ethics Bowl Fall 2018 Regional Cases* (published by Association for Practical and Professional Ethics) and the *AMA Journal of Ethics*. I have altered the formatting and corrected broken links.

HOW TO RESPOND TO CASE STUDIES: A BRIEF GUIDE

Case studies are meant to help you practice how to engage in “real life” ethical deliberation: the problems they present are often tricky, and solving them requires that you consider the needs and interests of multiple stakeholders (including patients, staff, the government, various companies, etc.). With this in mind, remember that the goal is to what you “think” or “feel.” Instead, you want to find a way to propose a solution that you think you could defend/explain to all those affected by it. (So: put yourself in the shoes of these medical professionals! Do your best to figure out a workable solution). While the details of each case will require a somewhat different response, you generally go through something like the following FIVE steps:

Step 1: Identify the Problem(s) and Describe the Morally Relevant Features of the Case. Before trying to solve a problem, it’s important to get clear on the nature of the problem(s). With this in mind, take some time to describe the main points of the case study in your own words, and identify what you think are the main ethical issues at stake (i.e., those you’ll be addressing later in the case study response). You should make sure to clearly identify any *assumptions* about the case you have made. You’ll also want to make clear who the various **stakeholders** in this case are (these are all the people/organizations who have a stake in the outcome). This will often involve reviewing the **sources** that are referenced within the case study.

This step is often overlooked, but it’s a hugely important one, as many “disagreements” about ethical issues are often a result of different people having wildly different views of what the “facts” are. Taking the time to make this clear ahead of time can save a world of trouble. In general, this should be no more than 15 to 20% of your essay (so, a half page of a three-page paper). You should NOT simply repeat the case study back to me—the goal in this step is to really narrow in on what is important.

Step 2: Identify MULTIPLE Possible Solutions or Approaches. After you are done with step 1, you should have identified one or more specific questions that need to be answered. For example, our question might be “What is the morally right thing for X to do?” or “What should the law/policy about Y be?” Now, we need to identify *more than one* possible answers to this question. In some cases, we’ll already know what X did (and we’re trying to figure out whether it was the right thing to do); in other cases, we’ll be starting from scratch. You should make sure to include both (1) obvious solutions (the ones you know people will bring up) and (2) “creative” solutions (ones that occur to you as you work through the problem). Make sure you describe each of these solutions/approaches in enough detail so that a reader can understand what each would entail.

Step 3: Determine Which Ethical Principles or Ideas Might Be Relevant, and Explain Why. As you start trying to solve the problem, you’ll want to think about what ideas might be most relevant. These might be general ideas (e.g., the idea of autonomy, or beneficence), specific policies (e.g., regarding things like abortion, euthanasia, etc.), or even a different case study with which you see similarities. Now, clearly and succinctly explain *why* these ideas are relevant. Don’t assume your audience will automatically know what you are talking about—take your time to explain, even if it seems obvious to you. This is a great place to bring in class material (from the notes, textbook, etc.), or from outside resources (though be sure to cite this).

Step 4: Argue for Your Chosen Solution. Now, go to work! Use the ethical ideas/concepts you’ve identified in step 3 to argue for ONE of the solutions in step 2. This is the “heart” of your response (and it may take up 50% or more of your essay), but you shouldn’t start on this step until you’ve worked through steps 1 through 3. While this doesn’t occur until relatively late in the process, you’ll want to make sure your **thesis statement** (that is, a statement about what your conclusion is re: this case) comes early in the essay.

Step 5: Consider Objections to Your Solution. To close, try to think about possible objections to your solution. These might include (1) common misunderstandings (which you can answer by clarifying) or (2) genuinely bad things about your solution (here, you’ll have to argue that your solution is still better than the alternatives). When doing this, you’ll be trying to take the point of the view of someone who favors one of the *other* solutions to the case study. When it comes to the exams, a failure to adequately deal with objections is often the difference between an A-level response and a B- or C-level response.

CASE STUDY 1: WHEN SYMPTOMS AREN’T VISIBLE OR MEASURABLE, HOW SHOULD DISABILITY BE ASSESSED?

CR is a 52-year-old woman who suffered a concussion in a car accident. CR struck the left side of her frontal bone against the car's dashboard and was transported by ambulance to a hospital. Computed tomography and magnetic resonance imaging ruled out hemorrhage, and imaging studies were negative. CR was scheduled for an outpatient visit with a local neurologist, Dr N, and was sent home with symptoms of headache, photophobia, nausea, and fatigue, which persisted. CR reported to Dr N about 1 week after the accident that she felt "hazy" and was crying a lot. Dr N encouraged CR to try to avoid stress, screens, and sensory overstimulation. CR used up her 2 weeks of vacation time to recover.

Now 1 year after the accident, CR's postconcussive symptoms are ongoing. She reports to Dr T, her primary care physician, that she's frustrated about not feeling able to return to work full time and to daily activities with family. She reports feeling guilty for resting, but sounds and light still frequently trigger disabling nausea and headaches. CR knows she needs time to heal, but she is concerned about losing her job, falling short on mortgage payments, and providing for her family. One problem is that CR's job requires nearly constant screen interaction, which also triggers debilitating symptoms. CR states that her manager has asked her to "step it up" and adds, "I look fine, so people don't understand what I am going through and are frustrated when it takes me so long to do things I used to do quickly."

CR presents disability benefits forms to Dr T and asks for help completing these forms. Without reliable serological tests or imaging studies to quantify CR's symptoms' severity or help determine her prognosis, Dr T consults Dr N. Both physicians are unsure about whether postconcussive syndrome^{1, 2} is a qualifying disability. They wonder how to respond to CR's request for help with the forms.

CASE STUDY 2: HOW SHOULD CLINICIANS ADDRESS A PATIENT'S EXPERIENCE OF TRANSGENERATIONAL TRAUMA?

Ashley Suah, MD and Brian Williams, MD

A retired veteran, Mr S enlisted in the US Army with hopes of giving his family a better life. He is an active Black elderly man with no significant illnesses or injuries before being brought to an emergency department (ED) after collapsing at home. Clinicians learn that, for about 3 months, Mr S has experienced early satiety (feeling full after consuming only a few bites of food), weight loss, and persistent fatigue. Following hospital admission, an endoscopic biopsy reveals localized gastric adenocarcinoma, and a surgical team, led by Dr D, evaluates Mr S for gastric resection.

Mr S's wife, children, and several grandchildren are present with him in the hospital. Dr D explains gastric resection to Mr S and his family, and Mr S clarifies that he does not want surgery because he is "unsure whether I would make it." Dr D asks him to say more about not wanting surgery. Mr S explains that, when he was young, his father had an operation for an infected foot ulcer. His father was discharged home the morning after his operation with minimal instruction on how to care for the wound and without any home resources to facilitate ongoing wound care. Despite the operation, the foot infection did not get better. Instead, the infection got much worse. His father's leg became rapidly necrotic after discharge home. The involved skin, fat, and muscles of his foot began to die as the infection spread rapidly up his father's leg. His father sought care from multiple surgeons, and no one agreed to care for him. Mr S remembers waiting for hours and hours in numerous emergency rooms with his father as they sought treatment. He remembers his father being accused by one nurse in an examination room of "not taking care of himself." Unfortunately, by the time his father was appropriately evaluated and able to be admitted to a hospital, the infection had spread all the way up to his thigh and hip. He was admitted to an intensive care unit and died the following day. Mr S explains that he worries this could happen to him, although times have changed. "Some things haven't changed. It's nothing personal against you, Doc. I just don't want this surgery." Dr D wonders how to respond.

CASE STUDY 3: FELONY AND ME

The Golden State Killer was linked to numerous murders and rapes through the 1970s and 1980s. Though the case had been cold for decades, law enforcement recently arrested a suspect. Investigators linked the suspect to the crimes by uploading his DNA profile under a pseudonym to a genealogy website that uses DNA samples to match relatives. A distant relative of the suspect uploaded a profile, and the familial match led law enforcement to the suspect.

This process took months. Investigators worked with genealogy consultants to construct numerous family trees, tracing the suspect's family back to the 1800s. They also used traditional police methods, looking through census and death records. They

finally narrowed their focus to one man who lived in the vicinity of the crimes, fit the killer's physical description, and was about the right age. A surveillance team was sent to observe the man and collect a discarded item for DNA testing. It was a match.¹

But the relative submitted his or her DNA for the purpose of genealogy—not to help catch criminals. A lawyer for the genealogy site reiterated: "The purpose [of the site] was to make these connections and to find these relatives. . . . It was not intended to be used by law enforcement to identify suspects of crimes." However, the lawyer admitted that it did not technically violate the site's policy to join for the purpose of catching criminals.² Indeed, most similar sites state that if presented with a warrant, the site will turn customers' genetic information over to law enforcement.³

Many find this a worrisome invasion of privacy, especially considering how popular genealogy services have become. As one ethicist who studies DNA forensics puts it: "This is really tough. . . . He was a horrible man and it is good that he was identified, but does the end justify the means?" One law professor agrees that this is problematic, especially because so much information can be learned about an entire family through a single family member's DNA. In other words, "[i]f your sibling or parent or child engaged in this activity online, they are compromising your family for generations." We cannot predict how this information may be used in the future.⁴

It is also important to remember that DNA tracing is not infallible, and sometimes it can lead to mistakes. For example, one woman's DNA showed up at numerous crime scenes throughout Europe, leading detectives to believe that they were on the trail of a serial killer. But it turned out that it was the DNA of a woman who worked in the factory that manufactured the cotton swabs that the police used to collect samples.⁵

On the other hand, considering the seriousness of the Golden State Killer's crimes, it is hard to argue against using any available information to find the perpetrator of such heinous acts. And the investigators only used the genealogy site after checking with a FBI lawyer who gave them the go-ahead, advising them it was legal. The lead detective, who had been looking for the Golden State Killer for over twenty years, was "blown away" with what the genealogy site could offer their investigation. It is easy to see the great potential these sites have for helping law enforcement identify and catch criminals. Protecting the public from these offenders may justify using genealogy sites and outweigh the privacy concerns involved.

CASE STUDY 4: RACHEL IDENTITY DISORDER

A new Netflix documentary *The Rachel Divide* delves into the life of Nkechi Amare Diallo, best known by her former name, Rachel Dolezal. Diallo was the subject of much controversy in 2015 when it was revealed that her biological parents were white even though she claimed to be (and had passed as) black for ten years. While many resent any further attention being paid to someone accused of both exploiting white privilege and appropriating black culture, one aspect of the issue has sparked an especially incendiary and divisive debate: Diallo's claim that being transracial is relevantly similar to being transgender. On the one hand, philosophers and social scientists argue that both race and gender are social constructs, and it seems to follow that, as such, both concepts can change over time to be more or less inclusive. On the other hand, critics of the comparison argue that there are relevant dissimilarities between being transgender and claiming to be transracial that render the comparison a false analogy.

When asserting her sincerity about her racial identity, Diallo uses language that mirrors the experiences described by the transgender community: "I feel that I was born with the essential essence of who I am, whether it matches my anatomy and

¹ Tim Arango, "The Cold Case That Inspired the 'Golden State Killer' Detective to Try Genealogy," *The New York Times*, May 3, 2018, <https://www.nytimes.com/2018/05/03/us/golden-state-killer-genealogy.html>; see also Tim Arango, Adam Goldman, and Thomas Fuller, "To Catch a Killer: A Fake Profile on a DNA Site and a Pristine Sample," *The New York Times*, April 27, 2018, <https://www.nytimes.com/2018/04/27/us/golden-state-killer-case-joseph-deangelo.html>

² Gina Kolata and Heather Murphy, "The Golden State Killer Is Tracked Through a Thicket of DNA, and Experts Shudder," *The New York Times*, April 27, 2018, <https://www.nytimes.com/2018/04/27/health/dna-privacy-goldenstate-killer-genealogy.html>

³ Rebecca Robbins, "The Golden State Killer Case Was Cracked with a Genealogy Web Site," *Scientific American*, April 28, 2018, <https://www.scientificamerican.com/article/the-golden-state-killer-case-was-cracked-with-a-genealogy-web-site/>

⁴ "The ethics of catching criminals using their family's DNA," *Nature*, May 2, 2018, <https://www.nature.com/articles/d41586-018-05029-9>

⁵ Sara Chodosh, "Consumer DNA tests can't tell you much, but they sure can get your relatives arrested," *Popular Science*, May 2, 2018, <https://www.popsoci.com/consumer-dna-tests-golden-state-killer>

complexion or not...I've never questioned being a girl or woman, for example, but whiteness has always felt foreign to me, for as long as I can remember. I didn't choose to feel this way or be this way, I just am.”⁶ While no one except Diallo can know whether her claims are indeed sincere or true, it seems theoretically possible that a person could legitimately identify as a race different from the one they were categorized as at birth. If the types of feelings described in the above quote would validate a person's gender identity, then could they also validate a person's racial identity? Rebecca Tuvel, assistant professor of philosophy at Rhodes College in Memphis wrote a provocative, and ultimately divisive, article in the philosophy journal *Hypatia* where she argues, basically, that if we accept some of the arguments supporting transgender people and identity and we confer rights and respect based on those arguments, then if the arguments supporting transracial people and identity are relevantly similar, “there's little apparent logically coherent reason to deny the possibility of genuine transracialism.”⁷

Tuvel and Diallo's critics argue that to compare being transgender to being transracial is to overlook or diminish the unique lived experiences, histories, and perspectives of both groups. Some appeal to the lack of parity in claims of transracialism. For example, while access to resources varies, there are still a wide variety of non-surgical options available to people who want to pass as a different gender or sex (but who may not want, or cannot afford, gender confirmation surgery). Such is not the case with race. It is far easier for any white person to pass as black or mixed-race than it is for a black person to pass as white; as Tre'vell Anderson states, “black people can't identify as white and move through the world as such. Our skin doesn't allow us such privilege and ability, like Dolezal's does.”⁸ Thus, some claim that transracialism is yet another expression of white privilege.

Another objection to parity between identifying as someone from a different race or culture and identifying as a different gender claims that to be a part of a culture is to have participated in, or been affected by, that culture's lived experiences and historical roots. These arguments imply that if one has not, by virtue of their privilege, been a target of the oppression and marginalization of a culture, and if oppression and marginalization is a necessary (but not necessarily sufficient) criterion for membership in that culture, then one cannot claim membership in that culture. Thus, Zeba Blay writes, “[t]ransracial identity is a concept that allows white people to indulge in blackness as a commodity, without having to actually engage with every facet of what being black entails — discrimination, marginalization, oppression, and so on. It plays into racial stereotypes and perpetuates the false idea that it is possible to “feel” a race.”⁹ And to those who argue that transwomen (male-to-female) are appropriating “womanculture,” Evan Urquhart, in a blog on *Slate*, replies that while women will normally have lived an experience of oppression earlier in their lives, “there's also the very real fact that being openly, visibly trans is a far riskier proposition than openly appropriating aspects of black culture is for a white person... Being identifiably trans, however, brings with it some of the most intense and unrelenting stigma, prejudice, and vulnerability to violence in our culture, particularly for people perceived to be dressing as women.”¹⁰

CASE 5: ORGANS AT A FUNERAL

Organ transplantation is the process of removing a healthy organ from a donor who may be living or dead and implanting that organ in the body of a patient with organ failure. In the United States alone there are over 100,000 people with some stage of organ failure on the transplant waiting list. “On average 20 people die every day from the lack of available organs for transplant.”¹¹ Although most people support organ donation, most do not choose to register as organ donors.

⁶ Denene Millner, “Why Rachel Dolezal Can Never Be Black,” NPR, March 3, 2017, <https://www.npr.org/sections/codeswitch/2017/03/03/518184030/why-rachel-dolezal-can-never-be-black>

⁷ Jesse Singal, “This Is What a Modern-Day Witch Hunt Looks Like,” New York Magazine, May 2, 2017, <http://nymag.com/daily/intelligencer/2017/05/transracialism-article-controversy.html>

⁸ Tre'vell Anderson, “Four takeaways from 'The Rachel Divide,' Netflix's new documentary about Rachel Dolezal,” Los Angeles Times, April 27, 2018, <http://www.latimes.com/entertainment/movies/la-et-mn-rachel-dolezal-netflix->

⁹ Why Comparing Rachel Dolezal To Caitlyn Jenner Is Detrimental To Both Trans And Racial Progress,” Huffington Post, June, 12, 2015, https://www.huffingtonpost.com/2015/06/12/rachel-dolezal-caitlynjenner_n_7569160.html

⁴⁰ ¹⁰ Evan Urquhart, “It Isn't Crazy to Compare Rachel Dolezal With Caitlyn Jenner,” *Slate*, June 15, 2015, http://www.slate.com/blogs/outward/2015/06/15/rachel_dolezal_caitlyn_jenner_how_transgender_is_different_from_transracial.html

¹¹ American Transplant Foundation (2019). Facts and Myths About Transplant. Online" at: <https://www.organdonor.gov/statistics-stories/statistics.html>

To address this apparent disconnect, on March 20, 2020, England enacted Max and Kierra's Law which transitions their system of organ donation from opt-in to opt-out¹². An opt-out system of organ donation presumes that, upon death, people would automatically consent to donating their organs to another person unless they had previously stated otherwise. In a presumed consent system one can still refuse to donate their organs but must explicitly opt-out. This contrasts with the opt-in model whereby one is presumed to refuse donation of their organs unless they have expressly consented to such a donation by registering as an organ donor. In 1979 Spain became the first country to adopt an opt-out system of organ donation. Spain now has the world's highest rate of organ donation.

Over the last 40 years many countries across the EU, Oceania, and South America have moved from requiring expressed consent to presumed consent and have seen significant increases in organ donation. However, some opt-out countries such as Luxembourg and Bulgaria have unusually low rates of organ donation. This has led some to suggest that the general correlation between presumed consent laws and increased donation rates is indicative of a third causal factor and not a case of the law, per se, strongly improving donation rates. According to some such critics, "In the absence of strong evidence, time and effort spent on legislative change misses the opportunity to focus on nonlegislative action, which could have greater impact."¹³ Examples of such non-legislative action include building a more robust procurement system including additional facilities, staff, and medical personnel trained and focused on recognizing potential organ donors.

Even granting evidence that suggests at least modest improvements in donation under presumed consent models, such systems raise questions about how, when, and why people may opt-out. For example, there is substantial disagreement about so-called "first person consent." Under first person consent families cannot override the patients' consent (presumed or express.) For example, "In Austria, the rate of donation quadrupled within 8 years of a presumed-consent policies being introduced. Under Austrian legislation, organs can be recovered irrespective of relatives' objections."¹⁴ This is in stark contrast to the situation in other countries. For example, "Even if you are on the Australian Organ Donor Register donation won't proceed without your family's consent." The difference in these countries policies make a substantial difference to some individuals and families.

¹² <https://www.organdonation.nhs.uk/uk-laws/organ-donation-law-in-england/>

¹³ 9 Willis, B. H., & Quigley, M. (2014). Opt-out organ donation: on evidence and public policy. *Journal of the Royal Society of Medicine*, 107(2), 56–60. <https://doi.org/10.1177/0141076813507707>

¹⁴ 0 Zink, S., Zeelandelaar, R., & Wertlieb, S. (2005) Presumed vs Expressed Consent in the US and Internationally. *AMA Journal of Ethics*, 2005;7(9):610-614 <https://journalofethics.ama-assn.org/article/presumed-vs-expressedconsent-us-and-internationally/2005-09>