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Jesús A. Díaz, *Ph.D.*
Philosophy
Kean University
Union, NJ 07083-7131

ETHICS ASSIGNMENT

NARROWING YOUR TOPIC

All assignments in this course are rehearsals to your Final Paper. This assignment stands midway between the Cultural Event and your Final Paper. The Cultural Event was your initial opportunity to apply what the course had covered up to the date of that assignment. In the Final Paper, you should display your mastery of all the skills taught during the entire semester. These are:

- Identify problems as prerequisites to research
- Narrow your topic—this assignment's purpose
- Awareness of moral problems in research
- Retrieve information (data) from databases
- Assess the reliability of sources
- Understand the difference between data and interpretation. Interpret the data you or others gathered
- Know when to paraphrase and when to quote directly
- Avoid plagiarism
- Format your scholarly apparatus correctly. "Scholarly apparatus" refers to the totality of endnotes, footnotes, in-text citations, notes, and bibliography

Previous assignments required me to narrow the topic; *you* narrowing the topic is this assignment's goal. Reinforcing the difference between data and interpretation is a secondary objective. I mimic the situation of a person who has read extensively about the intersection of health and social justice. Specifically, that person has read about the topics the section titled THE DATA covers:

A) Medical care and research in developed and developing nations

B) How economic, educational, social and other factors affect people's ability to receive medical care, give informed consent to such care or to participate in research trials

C) Research involving underserved populations and risks of exploiting them

D) Reasonable Benefits and Fair Treatment as competing proposals for biomedical research in developing nations to comply with the standards Nuremberg, Helsinki, and Belmont enunciate.

That person wants to write a paper, but she or he has collected more data and possible topics than a paper can contain; hence, after reading this document, *narrowing your topic* is your first step.

Occasionally, while surveying the bibliography, some students have found topics that interest them more than those I've outlined. Consult with me if that's the case with you. Whatever your choice, the assignment's purpose and requirements would not change.

In this course's website, review *Instructions for Selecting the Topic of Your Final Paper*. The advice there also applies to this assignment.

GUIDELINES FOR THIS ASSIGNMENT

A) No more than four pages typed, double spaced. Do not count the bibliography in the four-page limit. If your paper has four pages of text and a bibliography, your paper has four pages, not five. A sheet has two pages, front and back.

B) Retrieve from library databases and cite at least three peer-reviewed sources, none older than five years, dealing with your topic. Your bibliography may contain no more than one source I cite in this document or in its bibliography.

C) Use the citation format you prefer: APA, Chicago, MLA or any other.

D) The symbol ■ precedes sources you should read.

TURN TO PAGE 3

ETHICAL FRAMEWORK

Because they express recognized research norms, familiarity with the following three documents should help you frame your approach:

A) *Nuremberg Code*

https://drive.google.com/file/d/0B4c7pHi2WdWjOVU1TGo5alNMcEk/edit

Focus on points 1, 4, 5, 7, 9, & 10

B) *Declaration of Helsinki*

https://drive.google.com/file/d/0B4c7pHi2WdWjZFEtUEtVRTBwZFU/view

Focus on *General Principles*; *Risks, Burdens and Benefits*; *Vulnerable Groups and Individuals*; *Informed Consent*; *Use of Placebo*

C) *Belmont Report*

https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/

Focus on *Beneficence*, *Comprehension,* and *Selection of Subjects*

This assignment has gone through several versions, starting years before anyone suspected our generation would live through a pandemic. COVID-19 hit us about three years after I retired. Because I was not teaching the course, I did not modify or update this document, but I added to the bibliography items relevant to this assignment's focus on justice in public health and medical care. The *Water* bibliography in this course's website has a COVID section.

TURN TO PAGE 4

THE DATA

I. /SITUATION IN THE USA

(i)

We watched *The Deadly Deception* in class, about The Tuskegee Syphilis Experiment:

- WGBH, Boston, for NOVA (Producer), & Dilami, D. (Director). (1993). *The Deadly Deception* [documentary]. VHS & DVD. Retrieved April 9, 2017, from https://www.youtube.com/watch?v=qNa8CnC4sSU

Even after *Nuremberg* and penicillin becoming available, the American government denied syphilis treatment to African American men who did not know the federal government was using them as research subjects (see *Nuremberg*, point 1; *Helsinki*, points 19 & 20).

(ii)

Read Gerth et al. (2000); Ryan (2024); Jordan et al. (2017); Richtel et al. (2016); Grady (2016); Rogers et al. (2018):

- Gerth, J. et al. (2000, Apr. 23). Drug makers reap profits on tax-backed research. *New York Times*. The story is part of a series titled *Medicine Mechants*.

Gerth et al. describe the development of Xalatan, a breakthrough in the treatment of glaucoma, a leading cause of blindness. Despite financing the research, American taxpayers without insurance or with insufficient coverage may not benefit from the eye drops. Albert Russell is an example [see *Helsinki*, point 34; Belluck, et al. (2021, Jul. 19); Robins et al. (2023, Jul. 22).]

- Ryan, L. (2024, Apr. 11). Many patients don't survive end-stage poverty. *New York Times*.

A story similar to Albert Russell's. Physicians tell a homeless man with a life-threatening infection that antibiotics are not eradicating the malady; amputating his arm in the only treatment. He refuses, unless he finds housing. Homeless in the streets, lacking an arm would make him vulnerable to assault and robbery. Psychiatric evaluation revealed the man thought processes were logical and he was not suicidal. Unable to find housing, the patient died in a hospice. His death certificate will say sepsis is the cause of death; it should add end-stage poverty. The letter presents this and another case as examples of situations common in safety-net hospitals: "Medical textbooks usually don't discuss fixing your patients' housing. They seldom include making sure your patients have enough food or some way to get to a clinic. But textbooks miss what my medical students don't: that people die for lack of these things."

■ Jordan, M. et al. (2017, May 13). The painful truth about your teeth: You can work full time but not have the money to fix your teeth—visible reinders of the divide between rich and poor. *Washington Post*.

Some Americans pay over $1 billion/year for cosmetic dental procedures while others, lacking dental insurance or with insufficient coverage, have just one option: have their teeth pulled. Geographical areas populated by the working-poor suffer from a shortage of dentists and tend to lack fluoridated water. The story describes a free dental clinic where, for two days, volunteer dentists provided free care. During that period, they treated 1,165 patients, many with full-time jobs but uninsured.

■ Richtel, M. et al. (2016, Dec. 19). Harnessing the U.S. taxpayer to fight cancer and make profits. *New York Times*.

As with Xalatan, American taxpayers financed the initial research leading to CAR-T, an immunotherapy. Critics argue that patients buying the $200,000 treatment pay twice: first for the early tax-payer financed National Institutes of Health (NIH) research, later for the drug marketed by a for-profit pharmaceutical. Some argue it is unethical for industry to profit from NIH-financed research when taxpayers' access to the therapy depends on their ability to pay.[1]

■ Grady, D. (2016, Dec. 24). In cancer trials, minorities face extra hurdles. *New York Times*.

According to Grady, immunotherapy is the new frontier in the fight against cancer but most research subjects in oncology and other fields are white. Without a diverse group of subjects, investigators cannot find out if distinct populations react to treatment differently (see *Helsinki*, point 13). Also, Black men are underrepresented in prostate cancer research despite being diagnosed with and dying from the disease at twice the rate of their white counterparts:

■ Rogers, C. et al. (2018). Attitudes toward genomic testing and prostate cancer research among black men. *American Journal of Preventive Medicine, 55*(5S1), S103-S11. DOI: https://doi.org/10.1016/j.amepre.2018.05.028

[1] For more on immunotherapy see McGinley, L. (2017, May 28). "This is not the end": Using immunotherapy and a genetic glitch to give cancer patients hope. *The Washington Post*.

II. / SITUATION IN DEVELOPING COUNTRIES

(i)

Read the following with *Helsinki*, points 19, 20, & 34:

- McNeil, D. (2010, Oct. 1). U.S. apologizes for syphilis tests in Guatemala. *New York Times*.
- Carroll, R. (2011, Jun. 8). Guatemala victims of US syphilis study still hunted by the "devil's experiment." *The Guardian*.

As World War II ended, American public health officials worried about service members with sexually transmitted diseases returning home. To test penicillin's effectiveness, from 1946 to 1948 NIH physicians infected seven hundred Guatemalan prison inmates. As the Tuskegee men, these prisoners did not know they were being used as research subjects. NIH paid syphilis-infected prostitutes to have sex with the male prisoners. If this did not infect the men, researchers injected syphilis bacteria in them. Dr. John Cutler, who participated in the Tuskegee project and appears in *The Deadly Deception*, led the Guatemala study.[2] McNeil (2010) mentions two other studies where consent was absent: In the 1960s, investigators infected retarded children with hepatitis; in 1963, elderly patients were injected liver cancer cells.

During the Cold War, the American government, concerned about biological warfare, conducted experiments affecting thousands of unsuspecting Americans:

- Rubin, J. et al. (Producers & Directors). (2007). *The living weapon* [Documentary]. PBS Home Video. Retrieved May 4, 2024, from https://www.pbs.org/wgbh/americanexperience/films/weapon/

(ii)

In parts of Africa and Asia, the percentage of the population infected with HIV and the rates of HIV transmission are higher than in developed countries. Connor et al. (1994) report that from 1 to 2 mg. of AZT orally five times/day to the mother before and during labor, and to the infant during the first six weeks of life outside the womb, reduce by two-thirds the transmission of HIV from mother to infant. As of 1998, these dosages cost $800 in the United States. The annual public health budget in many developing countries is $5-22 per capita (Glantz et al., 1998b, footnote 11).

Mothers taking AZT must refrain from breast-feeding, so families with limited resources would have to buy baby formula. Due to water contamination, breast-feeding is the method of child rearing health experts in developing countries recommend. These circumstances bring to mind the 1970s allegations that multinationals marketing infant formulas in developing countries

[2] McNeil, D. (2011, Aug. 30). Panel hears grim details of venereal disease tests. *New York Times*.

led to increased infant mortality in those nations (Garson, 1977; Molander 1980; Newton 2000; Sasson (2016); Vogell, 2024):

https://www.unwater.org/our-work/integrated-monitoring-initiative-sdg-6/indicator-611-proportion-population-using-safely

https://www.youtube.com/watch?v=LCKsU4bPFOQ

https://www.youtube.com/watch?v=fgCwHD5SeHc&oref=https%3A%2F%2Fwww.youtube.com%2Fwatch%3Fv%3DfgCwHD5SeHc&has_verified=1

The third link requires signing in with a Google account. I accessed all three on April 9, 2017.

Health authorities in Africa and Asia thought that a more limited course of AZT might be effective; finding out required a trial. That trial raised three ethical problems:

1. Randomized trials, the gold standard in clinical research, have placebo arms (persons who do not receive the substance or treatment tested). This is not a moral problem when the trial's purpose is to discover if what is tested cures or manages a disease. This was the purpose with the investigations involving Xalatan and CAR-T. But experts knew that AZT combats HIV/AIDS. Assigning African and Asian women to the placebo group—to deprive them of effective treatment—was to let the natural progression of HIV/AIDS unchecked.[3]

Angell (1997, p. 847) explains this point:

> An essential ethical condition for a randomized clinical trial comparing two treatments for a disease is that there is no good reason for thinking one is better than the other. Usually, investigators hope and even expect that the new treatment will be better, but there should not be solid evidence one way or the other. If there is, not only would the trial be scientifically redundant, but the investigators would be guilty of knowingly giving inferior treatment to some participants in the trial. The necessity for investigators to be in this state of equipoise applies to placebo-controlled trials, as well. Only when there is no known effective treatment is it ethical to compare a potential new treatment with a placebo. When effective treatment exists, a placebo may not be used. Instead, subjects in the control group of the study must receive the best-known treatment. Investigators are responsible for all subjects enrolled in the trial, not just some of them, and the goals of the research are always secondary to the well-being of the participants.

- Was assigning African and Asian women to the placebo group ethical?

The women in the placebo group were not getting AZT because they were poor and their countries lacked the resources to buy it and/or the infrastructure and personnel to distribute it (see *Helsinki,* point 33; *Belmont*, Beneficence). Developed counties showed no willingness to defray the cost. That's why the investigators wanted to find out if a lower (presumably cheaper) dosage than used in developed countries would be safe and effective.

[3] "Natural progression" refers to the sequence of disease stages without medical intervention. With rare exceptions, untreated HIV infection leads to death.

2. Living in poverty, with little or no health care or education, were the women who volunteered for the AZT study able to provide the uncoerced informed consent *Nuremberg*, *Helsinki*, and *Belmont* require? Informed consent requires an elementary scientific understanding, which people with little or no education may lack (see *Belmont*, *Comprehension*). Living where medical resources are inadequate, mothers eager to protect their children from HIV/ADS are vulnerable to manipulation (Tafesse et al., 1998). French (1997) reports that despite briefings, participants in the African studies did not understand what a placebo is or why researchers use them; others did not know AZT existed. Their need to receive medical care for them and their offspring led them to join the study. Finding that ethics rules may not allow the trial in the United States surprised an Ivory Coast health official. See *Helsinki*, points 19 & 20 and *Belmont*, Selection of Subjects.

■ Titanji, B. K. (2012, May). TED: Ideas worth spreading. Retrieved April 9, 2017, from Ethical Riddles in HIV Research:

https://www.ted.com/talks/boghuma_kabisen_titanji_ethical_riddles_in_hiv_research

If link does not work, try:

https://drive.google.com/file/d/0B4c7pHi2WdWjSjdLMTViRDdBSVk/view?usp=sharing

The effects of education on research subjects are not limited to developing countries. Grady (2016) reports that, in New York City, lower educational attainment correlates with not understanding explanations or consents, having language barriers, not knowing about trials, and lacking transportation.

REASONABLE AVAILABILITY AND FAIR BENEFITS

3. Effective treatments should be available to all needing them (see *Helsinki*, point 34). Even if trials proved the hypothesis that lower AZT dosages block the transmission of HIV from mother to child, developing countries lack the resources to buy and distribute AZT. In other words, if lower AZT dosages work, developed nations will continue to provide treatment to their citizens without having placed them at risk. But developing nations may not benefit from trials in which their citizens participated (Glantz et al., 1998a).

Years ago, research in developing countries showed that vitamin A decreases infant mortality and a hepatitis B vaccine prevents perinatal transmission of the infection. These inexpensive interventions remain unavailable in the countries needing them but unable to pay; it is unlikely that expensive AZT would be (Lallemant, M., 1998).

The United States has the resources and the infrastructure to make medical treatment available to all within its borders. The profit motive and lack of insurance or insufficient coverage leads to cases like those described above (pp. 3-4). For developing countries, ethicists have proposed two ways of dealing with the ethical challenge: Reasonable Availability and Fair Benefits.

REASONABLE AVAILABILITY

Council of International Organizations (2002, p. 51) states, "any intervention or product developed, or knowledge generated (by research in poor communities) will be made reasonably available for the benefit of the population or community."

■ Council of International Organizations of Medical Science. (2002). *International Ethical Guidelines for Biomedical Research Involving Human Subjects.* Geneva: CIOMS. Guideline 10: Research in Populations and Communities with Limited Resources. Retrieved Mar. 3, 2017 from

https://cioms.ch/publications/product/international-ethical-guidelines-for-biomedical-research-involving-human-subjects-2/

Admitting we cannot correct global injustices overnight, Consensus Statement (1999, p. 833) adds:

> To define the highest standard of care practically attainable in the host country is difficult and may be different from the existing standard of care. A majority of us agree that, at the very least, the highest standard of care practically attainable in the host country should be provided to all study participants. There is no obligation to provide study participants with the highest standard of care attainable elsewhere in the world.

■ Consensus Statement. (1999, Mar. 6). Science, ethics, and the future of research into maternal infant transmission of HIV-1. *Lance*t, *353*(9155), 832-835. DOI: https://doi.org/10.1016/S0140-6736(98)10414-2

In other words, if developing country X hosts a trial, X's citizens who participated in the study must have access to X's highest standard of care, not to a higher standard of care in developed countries. A problem afflicts this view: The products of biomedical research should be available equally to all who need them. Moreover, whether or not therapeutic findings result from investigations, Reasonable Availability does not leave developing countries better off than they were before participating in biomedical investigations.

FAIR BENEFITS

Clinical research often proceeds in three phases, sometimes more: Phase I is the first human exposure to the substance or therapy investigated; often, Phase 1 aims is to find out if humans react as nonhuman animals did. Involving a group larger than Phase I, Phase II aims to confirm dosages and compare the drug or treatment under investigation with existing therapies; side effects found in Phase I are examined. Phase III, involving the largest number of participants, intends to confirm and refine earlier findings. Passing Phase III is necessary for the substance or treatment to reach the public.

https://www.nccn.org/patients/resources/clinical_trials/phases.aspx (accessed Oct. 6, 2019)

Reasonable Availability guides us only when phase III leads to new findings. We cannot apply it to phases I and II—when risks to research subjects are higher—or when Phase III is futile.

The Fair Benefits standard goes further:

> A exploits B when B receives an unfair level of benefits as a result of B's interactions with A.
>
> . . . .
>
> They (populations in developing countries that have been subjects in medical research) may be exposed to the risks of research, while access to the benefits of new, effective drugs and vaccines goes predominantly to the people in developed countries and the profits go to the biopharmaceutical industry. This situation fails to provide fair benefits and thus constitutes the paradigm of exploitation (Participants in the 2001 conference, 2002, p. 2133).

■ Participants in the 2001 conference on ethical aspects of research in developing counties. (2002, Dec. 13). Fair benefits for research in developing countries. *Science, 298*(5601), 2133-2134.DOI: 10.1126/science.1076899

Avoiding exploitation requires that underdeveloped countries participating in clinical research benefit regardless of the knowledge that may or may not emerge from the trials conducted within their borders. We must help those nations train health professionals, construct public health infrastructures, etc. The following chart, from [Participants in the 2001 conference. (2002), p. 2134] explains Fair Benefits:



For an expanded Fair Benefits chart see pg. 23 in:

Participants in 2001 Conference on the Ethical Aspects of Research in Developing Countries. (2004, May- Jun.). Moral standards for research in developing countries: From "Reasonable Availability" to "Fair Benefits." *Hastings Center Report 34*(3), 17-27. DOI: https://doi.org/10.2307/3528416

TURN TO PAGE 12

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[4] (1) As I wrote in *Instructions for Selecting the Topic of Your Final Paper*, DOIs often lead to publishers' websites, which invite you to buy what you can get for free in library databases. But publishers' websites often have, without charge, important information about the papers, e.g., how often they have been downloaded, cited, etc. Some publications lack DOIs.

(2) If a DOI does not work as it should, copy and paste it to your browser's search box.

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ETHNICITY AND RACE

∗ Abi-Rached, J. et al. (2024, Apr. 4). Nazism and the *Journal*. *New England Journal of Medicine, 390*(13), 1157-1161.[5] DOI: 10.1056/NEJMp2307319

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[5] With the heading *Recognizing Historical Injustices in Medicine and the Journal*, in 2024 *The New England Journal of Medicine* began publishing a series of articles dealing with the issues the heading covers. In this bibliography, ∗ precedes articles in the- series.

Bichell, R. et al. (2021, Jun. 6). For Black patients, an algorithm may help perpetuate harmful racial disparities. *Washington Post*.

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∗ Jones, D. et al. (2024, Jan. 4). Indigenous Americans—The *Journal*'s historical "Indian problem". *New England Journal of Medicine, 390*(1), 1-7. DOI: 10.1056/NEJMp2307311

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IS THERE A RIGHT TO HEALTH CARE?

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