

7.18. Right or wrong, researchers at Yale probably had no choice but to terminate the study. This research was probably funded by the United States government which adheres to strict standards for all research involving human subjects, regardless of where they live.

- Argument for terminating the study: The human subjects involved should be treated with the same level of care and respect as they would in the United States. If the Tanzanian government is not going to adhere to these standards, the study should not take place.
- Argument against terminating the study: Researchers should “relax” their ethical standards for human subjects research. Studying this population (pregnant mothers) could reveal new medical insights on how HIV is potentially passed on to the fetus. Further knowledge of this could benefit science and help other people around the world.

Which do you agree with? Do you side more with the Tanzanian mothers or more with the potential benefit to society? The accepted standard is to regard this study as unethical because the subjects are not provided with sufficient information on why the study is taking place. Also, knowingly withholding a medical diagnosis from the subjects (HIV/not) is clearly unethical.

7.25. (a) This is a violation of informed consent. The investigators should have alerted me before the study that my blood would be stored and possibly used for future research.

(b) The informed consent requirement has still been violated (confidentiality preserved or not), so the hard-line answer is “no.” This is still unethical.

(c) Whatever the eventual use, subjects should be aware of what the *possible* uses of their biological specimens might be. This could be outlined in the study protocol (that the subject reads and signs when giving consent). Regardless of whether confidentiality (or even anonymity) is guaranteed, certain types of research may violate the ethical principles of the subjects themselves. For example, what if my biological specimens were used for cloning? I would not be in favor of this.

7.28. This is now a famous example of unethical research. A full account of the Willowbrook studies is in

- Goldby, S., Krugman, S., Pappworth, M., and Edsall, G. The Willowbrook letters: Criticisms and defense. *The Lancet*, April 10, May 8, June 5, and July 10, 1971.

Goldby and Pappworth argued against the studies:

- It is unethical to perform an experiment on a mentally retarded child (or any child) when no benefit can result for that child.
- The institutionalized should not be used for human experimentation.
- Experimentation on children, even with parental informed consent, is unethical unless it is in the interest of the child.

Krugman did provide some compelling arguments in favor of the studies:

- There was no additional risk for the children. Under the normal conditions at the institution, children would have been exposed to the same strains of hepatitis anyway.

- Children had a lower risk of complications because they were housed in a special unit where there was little danger of exposure to other diseases.
- Children had the chance of benefiting from immunization.
- Children were obtained only with informed consent from parents.

Which side do you agree with? Remember, there were notable advances made in infectious disease research because of these studies. This research helped to learn more about hepatitis and to develop effective vaccines for certain strains of it.

7.32. (a) It is now regarded to be unethical not to have asked Ms. Lacks for permission to use her cells prior to her death. At the time, ethical standards for research on human subjects were not as strict as they are now in the United States. Still, this case does present some interesting questions, namely, “Does the benefit to society, perhaps to millions of people and future generations to come, outweigh the possible harm done to one individual in not obtaining informed consent?”

(b) I would want a complete description of how my cells were going to be used. Personally, I would have no problem with this if my cells were going to be used to treat chronic diseases like HIV/AIDS, TB, Alzheimer’s disease, etc. For me, the potential benefit to others would be payment enough.

7.40. The investigator should discuss with the students beforehand that the experiment will investigate cheating behavior. It is not ethical to obtain information on students covertly. This study might cause undue embarrassment to the students. Although causing embarrassment is probably minor, not being honest with the subjects is a violation of research ethics.