

Bad Blood at the Tuskegee Crossroads: Informational Ethics, Whistleblowing, and the Media


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How can we improve information literacy teaching methods in the health sciences?

This paper describes one possible solution in the application of the ACRL Framework to ethics and clinical research, with a focus on whistleblowing, the media, and the Tuskegee Untreated Syphilis Study. The design of the instructional activity includes a reading, video, lecture, assignment, and discussion essay.



Background

Senior Communication Disorders students in a three-credit-hour undergraduate information literacy class in a four-year, public master's level institution. INF 310 – Health Information for Practitioners and Consumers

Ethics in Clinical Research
Module of the class



Assignment

- Before class or during class, watch the TedX video on whistleblowing – Kelly Richmond Pope- How Whistle Blowers Shape History (12 minutes)
- Before class, read the article, “Tuskegee Truth Teller” by Carl Elliott
- Before class, read the textbook chapter on the Internal Review Board.
- During class, discussion about all three and PowerPoints. Quick Review of ACRL Framework.
- Students then choose one of the frames and discuss how it relates to whistleblowing and ethics in clinical research, specifically dealing with the Tuskegee study.
- Write 300 words



Learning Objectives of the Class and Assignment



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- ▶ After this class, the student will be able to
 - ▶ Describe the ACRL's Information Literacy Framework
 - ▶ Understand how the Tuskegee Syphilis Study and Peter Buxton's whistleblowing helped advance ethical clinical research
 - ▶ Be able to frame whistleblowing in the context of the Syphilis Study
 - ▶ Be able to discuss the role of the media in whistleblowing



The Tuskegee Study of Untreated Syphilis

- ▶ Subjects were 412 poor African American men with untreated syphilis conducted between 1932-1972
- ▶ The investigators with the U.S. Public Health Service wanted to study the natural history of syphilis
- ▶ Even after penicillin was known to be effective against syphilis the men were left untreated.
- ▶ In return the men were offered free meals and burial insurance.
- ▶ Students are rightfully outraged when they read about this study and their essays are typically strong.

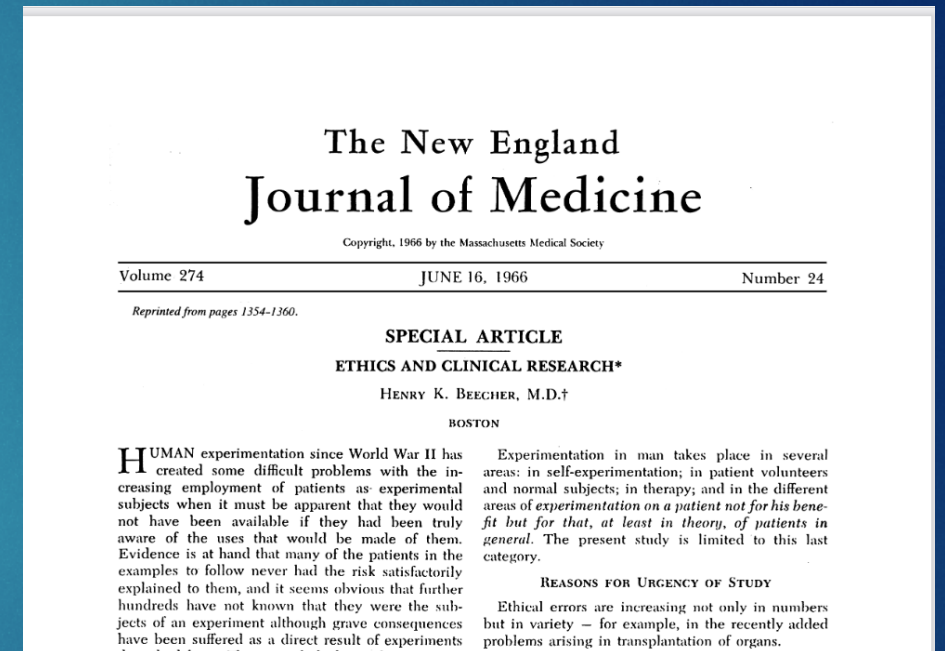


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Ethics and Clinical Research

- ▶ Henry K. Beecher wrote "Ethics and Clinical Research" in June, 1966, published in The New England Journal of Medicine.
- ▶ Prior to the IRB – gathered information of studies with unethical or questionably ethical studies
- ▶ Problem of Informed Consent – "The statement that consent has been obtained has little meaning unless the subject or his guardian is capable of understanding what is to be undertaken and unless all hazards are made clear." Ordinary patients will not knowingly risk their health or their life for the sake of "science."
- ▶ One category – Known effective treatment withheld



Lack of Ethics in Clinical Research



- ▶ The Tuskegee Syphilis Studies
 - ▶ Forty year study that continued after Penicillin had been found to treat the disease. (Treatment was withheld.)
- ▶ Nazi Holocaust Experiments and the Nuremberg Trials
 - ▶ Experiments conducted on Nazi concentration camp inmates
- ▶ United States Public Health Service, Disease Innoculation Study, 1946-48, Guatemala
 - ▶ Paid prostitutes to infect male inmates, mental patients, and soldiers
- ▶ Pfizer Trovan Study, Nigeria, 1996
 - ▶ Inadequately tested drug given to children, resulting in a host of severe side effects



IRB Ethics



- ▶ Immanuel Kant
 - ▶ Act in such a way that you treat humanity, whether in your own person or in the person of any other, always at the same time as an end and never merely as a means to an end.

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Information Literacy in the Health Sciences

- ▶ IL for our students is vitally important as they contribute to their disciplines through clinical research and do so ethically.
- ▶ Health Science students must learn how to follow ethical and/or legal guidelines.
- ▶ Health Science students must be prepared to stand up for the rights of their patients and subjects in clinical research.
- ▶ If you see something, say something.



Information Literacy Concepts

- ▶ Influence and exertion of authority
- ▶ Exploitation of privacy and the commodification of personal information
- ▶ Marginalization of certain voices due to the value of information being wielded by the powerful
- ▶ The importance of ethical and legal guidelines in dealing with information
- ▶ How does information empower authorities and disempower “those not having a fluency in the language and process of a discipline?”



Informed Consent?

- ▶ The 412 Tuskegee Research Subjects were told they had “bad blood” not an infectious disease
- ▶ They were persuaded to join the study by offering them free meals and by promising to pay their burial expenses in exchange for permission to autopsy their bodies.
- ▶ In 1932 when the experiment began, treatment was limited to a lengthy, toxic course of arsenic-based therapy
- ▶ In 1943, penicillin was discovered to cure syphilis
- ▶ Untreated syphilis can result in blindness, heart injury, insanity, and death.



The ethical role of the whistleblower

- ▶ Irwin Schatz, a Cardiologist from Detroit, is also credited with attempting to whistle blow about the study.
- ▶ Peter Buxton – a 27 year-old working in 1965 in San Francisco as a venereal disease tracker. Heard of a man in Alabama who was suffering from the latter stages of syphilis and had central nervous system damage.
- ▶ A doctor diagnosed the man and gave him penicillin.
- ▶ Public Health Service officials became upset because the doctor had treated a research subject who wasn't supposed to be treated
- ▶ Peter Buxton started investigating the study
- ▶ He called the Communicable Disease Center who sent him a huge folder of information regarding the study. Buxton was outraged.



Nuremburg Code



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- ▶ Buxton came to America as an infant with his Jewish Czech father and Catholic Austrian mother.
- ▶ He read about the Nuremburg code that states “The voluntary consent of the human subject is absolutely essential.” It also directs researchers to protect subjects from disability, injury, or death, no matter how remote the possibility.
- ▶ Buxton equated the Tuskegee Study to the German war crimes and decided he had to do something.
- ▶ John Cutler the chief investigator said they were within their rights to conduct the study because the subjects had volunteered.



The Media

- ▶ Buxton elicited the help of a journalist friend, Edith Lederer, a young AP reporter at the time
- ▶ Lederer took the information to her boss and he wanted a more experienced journalist to write the story. Jean Heller wrote the article that appeared in the New York Times on July 25, 1972, "Syphilis Victims in U.S. Study Went Untreated for 40 Years."

Syphilis Victims in U.S. Study Went Untreated for 40 Years: SYPHILIS VICTIMS GOT NO THERA

By JEAN HELLER The Associated Press
New York Times (1923-Current file); Jul 26, 1972;
ProQuest Historical Newspapers: The New York Times with Index
pg. 1

Syphilis Victims in U.S. Study Went Untreated for 40 Years

By JEAN HELLER
The Associated Press

WASHINGTON, July 25—For 40 years the United States Public Health Service has conducted a study in which human beings with syphilis, who were induced to serve as guinea pigs, have gone without medical treatment for the disease and a few have died of its late effects, even though an effective therapy was eventually discovered.

The study was conducted to determine from autopsies what the disease does to the human body.

Officials of the health service who initiated the experiment have long since retired. Current officials, who say they

have serious doubts about the morality of the study, also say that it is too late to treat the syphilis in any surviving participants.

Doctors in the service say they are now rendering whatever other medical services they can give to the survivors while the study of the disease's effects continues.

Dr. Merlin K. DuVal, Assistant Secretary of Health, Education and Welfare for Health and Scientific Affairs, expressed shock on learning of the study. He said that he was making an immediate investigation.

The experiment, called the Tuskegee Study, began in 1932 with about 600 black men,

Continued on Page 8, Column 1



The Tuskegee Experiment

- ▶ 28 men died from syphilis
- ▶ 100 died from syphilis complications
- ▶ 40 wives were infected
- ▶ 10 children born with congenital syphilis



The Assignment



INF 310

- ▶ Students watch the TedTalk about whistle blowing and read the article about Peter Buxton and the Tuskegee Untreated Syphilis Study
- ▶ Things for them to think about
 - ▶ Was informed consent granted?
 - ▶ What is the media's role in whistle blowing?
 - ▶ When you look at the ACRL Framework, which Frame applies to this study?
 - ▶ Why do you think this study was allowed to continue when many people were aware of it?



Leading Prompt Questions

- ▶ What role did the influence or exertion of authority play in determining what was right or wrong in the Tuskegee Syphilis study?
- ▶ How was “privacy and the commodification of personal information” exploited?
- ▶ What was gained by the Tuskegee Syphilis Study in terms of policies and procedures in dealing with human subjects (IRB)?
- ▶ How was the “value of information wielded by powerful interest in ways that marginalized certain voices?”
- ▶ Talk about the concept of “information privilege” in regards to the Tuskegee study.
- ▶ Was there a point when the study would have had an “appropriate scope of investigation?” What was that point and why?



Prompt Questions cont.

- ▶ Was there a way that the investigators could have followed ethical and/or legal guidelines? Did they follow one or the other?
- ▶ How did the Tuskegee study empower authorities and disempower “those not having a fluency in the language and process of a discipline?”
- ▶ Or explore another topic that relates to the student and the ACRL framework. You may want to read more about the study. *Bad Blood* is an excellent book that is available in the library about the Tuskegee Syphilis Study.



Utilize the ACRL Framework for Information Literacy for Higher Education – Which Frame Resonates with you for this topic?

- ▶ Authority is Constructed and Contextual
- ▶ Information Creation as a Process
- ▶ Information Has Value
- ▶ Research as Inquiry
- ▶ Scholarship as Conversation
- ▶ Searching as Strategic Exploration



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Framework

- ▶ Two additional elements—Knowledge Practices and Dispositions
- ▶ Knowledge Practices – “demonstrations of ways in which learners can increase their understanding of these information literacy concepts.”
- ▶ Dispositions – “describe ways in which to address the affective, attitudinal, or valuing dimension of learning.”
- ▶ Students will include appropriate Knowledge Practices and Dispositions in their essay





ACRL Framework

At the heart of this Framework are conceptual understandings that organize many other concepts and ideas about information, research, and scholarship into a coherent whole.

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Essays – Which Frame did the students choose to evaluate?

- ▶ Information has Value – 12
 - ▶ Marginalization within the systems that produce and disseminate information
 - ▶ Information privilege
- ▶ Authority is Constructed – 10
 - ▶ Different types of authority – societal position, subject expertise
 - ▶ Question traditional notions of granting authority
- ▶ Research as Inquiry – 1
 - ▶ Determining an appropriate scope of investigation
 - ▶ Demonstrate intellectual humility
- ▶ Searching as Strategic Exploration -1
- ▶ Didn't specify a frame – 5 (Information Privilege and Privacy)



Evaluation Methods

Pre and post-tests
given during the
semester to assess
knowledge practice
outcomes

Discussion essay via
Canvas

Results

Post assessment data indicated
that students had a better
understanding of the value of
health information within the
context of the Tuskegee
Untreated Syphilis Study and
Peter Buxton's actions



Discussion Assignments

Purpose: Reflect on what we're discussing in class and what you're reading and viewing outside of class and answer the discussion question in Canvas. Each discussion is worth 20 points.

Directions:

- Questions based on class discussion, readings, and student's selection
- Using the grading criteria below, student will respond to questions
- Responses will be at least 300 words.

Rubric

Grading Criteria for Discussion Questions

Each discussion question answered for class is worth a maximum of 12 points. Responses will be evaluated according to the following rubric.

Components	5 points	3 points	2 point	1 points
On Time	Entry is completed by class time (6:00 pm) on the due date.	Entry is 1 day late	Entry is 2 days late	Entry is more than 2 days late or not completed
Content	Entry shows critical thinking skills and contains a well-thought out answer to each question.	Entry shows critical thinking skills and well-thought out answers to some questions.	Entry rambles off topic.	Entry is incomplete or irrelevant.
Quality	Expresses insights or reflections in your own words to each question.	Express insights or reflections in your own words to some of the questions	Summarizes information but does not express reflections or insights.	Entry is incomplete or irrelevant.
Mechanics	Effective use of spelling, grammar, or punctuation. Uses a college level tone.	Contains some errors in spelling, grammar, or punctuation. Uses a semi-formal tone.	Frequent errors in spelling, grammar, or punctuation. Uses a semi-formal tone.	Excessive use of jargon or slang. Tone is too informal for class.



Conclusions

The ACRL framework addresses many of the difficult concepts inherent in health science information literacy instruction and provides an improved outline of how to teach the complexities of the ethical use of information.



Citations

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