Individual Rights vs. Medical Responsibility: Human Experimentation in the Name of Science

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“At the universities, the theories had to be validated by experiments. It was unquestioned that advances in medicine (as in natural science) could be achieved only through the inductive method of formulating a hypothesis and testing it, by subjecting it to revision and verification in a controlled series of empirical observations.” – Michael Krater

Humans have a right to life. Throughout humanity’s existence, illness has threatened that right. For life’s protection, cures were developed, and to develop them experimentation was needed. Specifically, human experimentation has been both instrumental and extremely controversial. Because the end result of any experiment cannot be perfectly predicted, human experimentation in medicine has mercifully saved myriads of human lives but obliterated countless others.

Therefore, rules must be established in order to maximize benefit and minimize loss of life. To achieve this, doctors’ and patients’ rights and responsibilities must be outlined. The penning of the Hippocratic Oath in about 400 BC provided the first step toward such guidelines and protections. Although these ethical codes govern many decisions, they are not always clear cut. In fact, it is impossible to make a generalization of these rights and responsibilities as only rarely is there a “textbook case;” the treatment of every patient is different in some way, be it their age, wealth, beliefs, medical knowledge available at the time they lived, or some other unforeseen factor that alters what must be done in experimental research and treatment.

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1 Michael Krater, *Doctors Under Hitler*, (Chapel Hill: North Carolina UP, 1989), 225
From the earliest medicinal discoveries and treatments, the physician has had ultimate authority on what to administer to a patient.\(^4\) It was not until the technological revolution in the mid-1960s when medical experiments were conducted to discover new treatments and technologies to potentially benefit patients. These experiments and their results soon raised ethical issues. Often the subjects of the experimentation and the recipients of newly discovered treatments were unwilling participants. In some cases, these patients died after being forced to undergo such experimental procedures. There were no guidelines in the Oath on these matters, so a new principle had to be established. This principle became known as “informed consent,” meaning that the potential subject or patient was entitled to all information about his situation in order to decide what was best for him or herself.\(^5\)

Informed consent was implicitly established as early as 1776 in the United States’ Declaration of Independence with the human right to “life, liberty, and the pursuit of happiness.” However, it was not until 1914, through the legal case Schloendorff vs. the Society of New York Hospital, that informed consent became law anywhere in the world.\(^6\)

Cures are commonly the focus of medical research trials. However, prevention techniques such as vaccination were also developed through experimental human research. Notably, smallpox was a devastating disease that is believed to have emerged around 10000 BC and utterly devastated the world until its official eradication in 1980 which arose from vaccine development.\(^7,8\) This monumental eradication of a devastating disease directly stemmed from the

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emergence of vaccination and human research which facilitated that emergence. Inoculation, an introduction of a virus into individuals by injection of infected material directly beneath the skin, was the first step in developing vaccination and protecting citizens worldwide against many diseases. The first practitioner of inoculation is not documented. However, it is known that inoculation and similar practices were in place as early as the tenth century AD – Indians protected against smallpox by blowing scabs from the disease up an uninfected person’s nose. This method provoked a mild form of the disease and also effectively immunized the person. Unfortunately, neither nasal sufflation nor any of the other various forms of inoculation was a perfect treatment. The smallpox contracted through this ingestion was usually milder but could still be deadly. Moreover, syphilis and other diseases were not uncommonly transmitted by such methods, which led to still more deaths.

Therefore, the responsibility of the medical profession to act in the best interest of their patients dictated a new solution was needed. Edward Jenner discovered it by forcibly injecting the son of one of his servants with cowpox, a disease similar to smallpox but found only in cows, to see if he would become immune to smallpox. Although the procedure provided excellent protection to the few private parties and physicians who utilized it, it was at first widely ignored. As other people began to try the procedure at Jenner’s urging, however, they found the results of vaccination were far better than those of inoculation. Thomas Jefferson was among

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10 Ibid
11 Ibid
12 Riedel, “Edward Jenner and the History of Smallpox and Vaccination”
13 Ibid
14 Riedel, “Edward Jenner and the History of Smallpox Vaccination”
these skeptics and experimented with the new vaccine upon his slaves before accepting vaccination on his family. By today’s standards, the vaccination experiments conducted by Jenner as a scientist and Jefferson and other civilians were immoral due to the lack of subjects’ informed consent, although no such principle existed at the time. Either way, they provided the world a gift of limitless value.

Although vaccination almost certainly would have been developed eventually, it is equally certain it would have taken much longer to become a general practice, as evidenced by the fact that for three months Jenner could find no volunteers to try his new procedure. This adds to the idea that medical rights and responsibilities are circumstantial. Due to informed consent not yet being established, and the results of the experiment being enormously positive, people were willing to overlook the abuse of individual rights.

Another important result of Jenner’s innovation is the development of the yellow fever vaccine. At the turn of the twentieth century, yellow fever was among the most potent and deadly diseases in the world but still could not be contained. As an American Army scientist stationed in Cuba in 1900, Walter Reed came to the realization that if it could be proved for certain that mosquitoes were the only carriers of yellow fever, preventive measures could be implemented. In this unusual case, members of the committee actually experimented upon themselves. After being subjected to the bite of a yellow fever-carrying mosquito, the subjects awaited their fates. In the end, several died to prove Reed’s theory and provide a critical new avenue of research in developing the eventual yellow fever vaccine.

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15 Harriet A. Washington, Medical Apartheid: The Dark History of Medical Experimentation on Black Americans From Colonial Times to Present. (New York: Harlem Moon, 2006), 59
16 Riedel, “Edward Jenner and the History of Smallpox and Vaccination”
This particular case of human experimentation is important when discussing medical ethics for one prominent reason. The positive results of this experiment establish the underlying principle that, assuming all necessary responsibilities and guidelines of the time and situation are followed, it is considered acceptable to allow the individual right to death in the hope of saving multitudes.

Merely two years after Reed’s self-experimentation, Marie and Pierre Curie were able to isolate the first known quantities of radium chloride.\textsuperscript{19} During the first years immediately following its discovery, this became a widely used health product. In fact, Dr. John MacLeod treated lesions caused by varieties of tuberculosis with radium radiation therapy. These treatments were all successful.\textsuperscript{20} Knowing that the use of radium was discontinued in the 1980s because of the overwhelming evidence suggesting its threatening properties and then the development of safer alternatives, this success rate is incredible.\textsuperscript{21} Likely, it stems from treatment never being given for more than a week at a time.\textsuperscript{22} Conversely, this deadly agent was the precursor to chemotherapy, which is a common cancer treatment.

Unfortunately, multiple businesses took this early success as a sign that they could market all kinds of radium-based treatments and proceeded to sell products for which they had no strong basis to consider safe, undeniably ignoring basic human rights and medical and business responsibilities in one fell swoop. Notably, \textit{Radihor}, a “Certified Radioactive Water” containing radium was sold and ingested incessantly by industrialist Eben Byers, who inevitably

\textsuperscript{21} Dronsfield and Ellis, “Radium – A Key Element in Early Cancer Treatment”
\textsuperscript{22} MacLeod, 1366
died from overexposure to radiation. Additionally, Marie Curie’s close and frequent work with radium hindered her body in combatting a form of pernicious anemia and facilitated her premature death.

Essentially, the entire era of medicine during which radium was considered a healing agent evolved into an ongoing human experiment to determine if and how any form of radiation could be used in medicine. This experimentation adhered to the rights and responsibilities of the medical profession in that the professionals operated under the knowledge of the time with the utmost care to protect its patients. It was more the irresponsibility of industry and consumers, who had little caution or reservation when it was found that radium could be a boon to health that led to the most deaths by radiation. As one who would eventually accidentally kill herself in the name of providing a means to cure debilitating disease, perhaps Curie can best summarize radium experimentation’s ethical constitution; “We must not forget that when radium was discovered no one knew that it would prove useful in hospitals. The work was one of pure science. And this is a proof that scientific work must not be considered from the point of view of the direct usefulness of it.”

In a similar manner to Walter Reed and his fellow scientists, Marie Curie responsibly exercised her rights and sacrificed herself for the purpose of providing something that would eventually save countless human lives.

Humans by nature are emotional, and it is not uncommon for emotion to cloud judgment. Because humans are in this way susceptible to outside influence, this desire for the greater good all too easily tends toward exploitation and the megalomaniacal. Despite doctors’ obligations to their patients, they are just as susceptible to unhealthy ambition.

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23 Dronsfield and Ellis, “Radium – A Key Element in Early Cancer Treatment”
25 Marie Curie, 1921, Ord. in Dronsfield and Ellis, “Radium – A Key Element in Early Cancer Treatment”
For example, while the atomic bomb was being developed in World War II, the American military needed volunteers to test prolonged radiation exposure and the effects on the human body. Seeing as how the bombs promised to bring America immediate victory, scientists were never short of civilian volunteers. They also exposed many military personnel to radiation without their knowledge. Needless to say, participation in such experimentation was not in the best interest of the subject – through Radithor and Marie Curie’s radiation facilitated death in 1934, radiation had already accrued a reputation in the scientific community for being detrimental to health, even if the extent to which it was dangerous was not yet fully known. Knowing this, the military proceeded under the assumption that harm was likely to be done to the subjects. Neither the civilian volunteers nor the soldiers were sufficiently informed to the immense potential for disaster and several fell ill from the radiation. Clearly the “right” to volunteer was unethically exploited by an irresponsible government disclosing insufficient information to potential human subjects.

This sense of patriotism manifested to a much further extreme on the other side of the lines during the same war. Josef Mengele, a National Socialist scientist whose views were so extreme it is difficult to reconcile them with the term “patriotic,” believed he was morally correct when he conducted experiments on Jewish captives at Auschwitz, a concentration camp in Germany, in an attempt to perfect the German race. The experiments Mengele conducted on his un-consenting subjects included needless amputations, mass sterilization, and bone marrow

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27 Andrew Golizsek, *In the Name of Science: A History of Secret Programs, Medical Research, and Human Experimentation*, (New York: St. Martin’s Press, 2003), 117
28 Ibid, 117
transplants, among incalculable others.\textsuperscript{30} Often, he brought patients to incredible suffering and the brink of death before killing them. Mengele at one point in time attempted to "perfect" children's eyes by injecting dyes into them, which often caused infection or even blindness in the final hours before they were condemned to death.\textsuperscript{31} Similarly, he injected twins with typhus merely to observe differences between the twins' reactions only to send them to be gassed when their usefulness was over.\textsuperscript{32}

Mengele's rights-abusing actions are considered to be among the most unethical in the world, but as disgusting as Mengele's abuse of human rights seems today, in National Socialist Germany his research attempting to genetically create the perfect human was a moral responsibility.\textsuperscript{33} Since the Jewish were culturally viewed as less than human, the ethics of Nazi Germany were not violated.

Due to the atrocities committed by Mengele and other Nazi scientists in their pursuits of knowledge, world leaders decided new limitations had to be set as to how human experimentation could be conducted without violating the rights of the subjects.\textsuperscript{34} To this end, a new set of principles guiding ethical rights and responsibilities in the medical profession was written to reflect changes in the world and its new knowledge and philosophies. This code came to be called the "Nuremberg Code," and included some of the principles of the traditional Hippocratic Oath but ignored others. Notably, the first clause was a new principle affirming that "the voluntary consent of the human subject is absolutely essential," and that the subject "should have sufficient knowledge... of the subject matter."\textsuperscript{35}

\begin{footnotes}
\item[30] Ibid, 31-32, 37
\item[31] Ibid, 34
\item[32] Posner and Ware, 40
\item[33] Robert Jay Lifton, Qtd. in Posner and Ware, Mengele: The Complete Story, 49
\item[34] Rothman, Strangers at the Bedside, 61-62
\end{footnotes}
Despite this code having been composed to guide the ethics of medical practices in America, it never became a legally binding document, and in fact was only nominally publicized and practiced. Because the Nuremberg Code failed to hold prominent legal authority, yet another set of guidelines inarguably had to be written, with yet more minor modifications to provide for new technologies. However, the Code’s principles are referred to and indirectly used through more current ethical codes. Most prominent of these is the Declaration of Helsinki, written in 1964, which makes special note that no research can ever take precedence over individual rights.

Even this Declaration is not the final word on medical rights and responsibilities concerning human experimentation. Along with the passage of 19 other acts after its initial signing, it has been revised nine times to answer concerns of time, culture, and philosophy of the world. This validates the idea that rights and responsibilities in human experimentation are ultimately variable.

Without human experimentation as a platform to research potential medical innovations, vaccines, cancer treatments, and other medical marvels would not have been developed as soon as they did. Thus, without human experimentation, countless lives would have needlessly been lost during the delay of discovery in the years of less efficient research. On the other hand, millions of Jews died because their rights were ignored and immoral responsibility was thought to be completely moral to some doctors in Nazi Germany. Moreover, before the perfection of

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36 Rothman, Strangers at the Bedside, 62
39 “WMA Declaration of Helsinki”
40 Posner and Ware, Mengele, 76
inoculation and radiation therapy, countless human beings died from the irresponsible propaganda founded upon incomplete information.

Medical science has evolved so rapidly that current treatments would be unimaginable for citizens of even a century or two ago. In most cases, this knowledge was derived from the results of human experimentation. Essentially, the fact that experimentation continues illustrates how unavoidable it is.41 And however obvious this may seem, it reflects that human experimentation is a right and even responsibility of medical professionals.

All in all, there is not one definitive answer for every single decision doctors have to make, for scarcely is there something so simple as a textbook case, especially where human rights and doctors’ responsibilities are involved. Nonetheless, so long as individual rights are protected, human experimentation is a responsibility of the medical profession to develop new means of protecting civilization. As notable surgeon and pathologist Sir James Paget remarked in 1906, “The last experiment must be on man.” 42

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42 House of Commons, Parliament of Great Britain, *Reports from Commissioners, Inspectors, and Others: Thirty-eight Volumes*, Vol. 41, Google Books, (February 12 – August 28, 1907), http://books.google.com/books?id=SPwLAQAAIAAJ&pg=RA1-PA131&dq=%22The+Last+Experiment+must+be+on+Man%22+James+Paget&hl=en&sa=X&ei=zHn-UprkJ8SikQkICoDg&ved=0CCkQ6AEwAA#v=onepage&q=%22The%20Last%20Experiment%20must%20be%20on%20Man%22%20James%20Paget&f=false (accessed January 7, 2014)
Primary Sources


Arita’s recollections of the procedures developed for eliminating smallpox were extremely helpful in that they were able to connect in my mind exactly how Jenner’s procedure of vaccination became such an important tool in eradicating disease.


Finding this article on the Internet was a boon to my research, as it gave me insight into established procedures for research trials involving humans from a doctor who had personal experience with such experiments. Without this knowledge, my analysis would have been much weaker because I would not have been able to draw several conclusions without knowing exactly how human experimentation is conducted.


Being the most current set of ethical codes, but having been revised nine times, this gave me insight as to how ethical philosophies in the entire field of medical ethics evolves rapidly, as well as the current frame of mind the world’s medical ethicists hold.

<http://www.archives.gov/exhibits/charters/declaration_transcript.html>

When one so much as mentions the rights of the individual, they must consider the United States’ Declaration of Independence from Great Britain, as it is the foundation for the philosophy America holds dear in believing the right of the individual is inarguably the most important aspect of a person’s life.


The case study of uninformed consent being beneficial to the recipients was very informative and gave me the idea that all experimentation must be considered in light of what occurs at the time of the experiment and cannot be accurately judged with a current perspective.


This article from the British Medical Journal was written in 1904 by a doctor who personally conducted research with the radioactive element Radium as a cure for disease (specifically varieties of lupus.) This article is invaluable to me because it presents concrete proof that good results can come of medical experimentation, and provides a counter-perspective to the knowledge that Radium was also a major factor in the death of at least one person, even though they were using it for medical reasons.

This news article from the New York Times is an obituary for Marie Curie’s death. It provided information as to how she died, and since the cause indirectly was radiation, I was able to utilize the knowledge as evidence to the argument that experimentation can yield surprising but fruitful results.


The article Professor Slosson writes to defend the point of view that the knowledge gained from experimentation takes precedence over individual life was very important for my paper because it presents an unusual argument to consider and analyze when I drew my final conclusion.

Moreover, it helped me analyze how ethical human experimentation is, even though I disagreed with his assertion that at any time or place, any sacrifice in the name of science is worth it.


<http://www.hhs.gov/ohrp/archive/nurcode.html>

The Nuremberg Code is a document outlining the principles guiding medical ethics as decided by those who had recently seen the atrocities unheralded human experimentation. This illustrates perfectly how ethics are in many cases situational – without Mengele’s and others’ horrid works, the code would not have been written. Knowing this, I was able to conduct more detailed analysis in my paper.


<http://classics.mit.edu/Hippocrates/hippooath.html>
Being able to read the first widely accepted document outlining ethical codes in medicine has proved invaluable, as it has enabled me to construct analysis and argument dealing with the chronological aspect of my paper.

Secondary Sources


This article I obtained from the online magazine *Education in Chemistry* opened a new avenue in research concerning nuclear medicine, how it was used and misused, and its effects past and present.


In a similar manner to Arita’s recollections, this article from the Yale Journal of Medicine was able to provide information as to what happened after the experimentation. From this article, I was able to learn more precisely how Reed’s research group’s sacrifices positively affected the entire field of medicine and the success in suppressing yellow fever.


When I synthesized a portion of the information in this work with that found in *Undue Risk*, I was able to piece together a comprehensive picture of American military experimentation during World War 2. In particular, this work gave me specific details that were not present in *Undue Risk*, including exactly who was exposed to nuclear fallout and if any of them fell ill.

This online book accessed through the National Center for Biotechnological Information allowed me to present a brief account of the entwined histories of vaccination and smallpox. Utilizing this short introduction, I feel I more effectively presented how vaccination and human experimentation progressed as time passed.


Out of this entire compilation of reports, I only amassed one fact. This was the all-important ending quote from Sir James Paget that “the last experiment must be on man.” Although short, this aphorism epitomizes exactly that, despite all the potential complications human experimentation can bring, it is an inherent necessity of society.


Most notably, this work lent me a powerful leading quote to capture readers’ attentions.

Additionally, the quote and the remainder of the book helped me develop my thesis.


This work enlightened me to a few key aspects of the evolution of medical experimentation ethics, mainly the business side of medicine’s influence on research, and a basic conception of research held by the public with evidence to support the assertion.

This work, obtained through the Interlibrary Loan Service, gave me a general background on American radiation during World War 2 that I combined with *In the Name of Science* to provide an analysis of wartime ethics in America. Additionally, I learned of a committee of scientists who were willing to experiment upon themselves in the name of finding a cure for yellow fever, even if it meant death.


From this document I found on the web, I was able to find numerous examples of debate concerning medical ethics. Being a legal paper, the analyses of multiple doctors it provided were able to emphasize the legal rights both patient and doctor have. Especially, I was able to find a summative analysis of the *Schloendorff vs. the State of New York Hospital* case that evolved to be the defining legal case establishing informed consent as a law in the United States.


This work, another obtained through Interlibrary Loan, was very helpful to me because it illuminated the terrifying incidence of human experimentation at Auschwitz, the German concentration camp. Even more importantly, I learned how even though everything that happened there is now considered horrible, it occurred at the time where that school of thought was completely ethical. This is able to strengthen the assertion that ethics are at least to some degree subjective and easily changeable.

Here I was introduced to a very important part of my paper in the form of smallpox and vaccination. Not only was I able to isolate experimentation that has provided the basis for many cures today, but I also learned of the harmful effects this experiment were occasionally incurred. As smallpox was a true plague, it was particularly notable as a high-impact turning point in history.


In reading this book, I was provided many provocative questions I would end up discussing in my research paper. Additionally, I learned a few basic ideas and ethical code that gave me a good starting point for my research. As this was one of the first works I read through, it was incredibly helpful in directing my thesis and research toward where would eventually wind up.


This webpage was very helpful in both illuminating the frequent adjustments human experimentation and general medical rights and responsibilities undergo, and in providing a great source if ideas unto which I could research.


This compilation was an excellent addition to my paper as it encompassed the idea of variability in medical philosophies on who holds certain rights and responsibilities and noted that this variability can stem from many factors, including individuals themselves.
. The Patient as a Partner: A Theory of Human-Experimentation Ethics.


This informative work has been very useful to me as it has alerted me to many issues within the field of medical ethics and human experimentation codes that provided me with multiple ideas for my research. Additionally, it presents some arguments and issues that I have considered and either supported or refuted in my paper.


This work gave me a couple of specific examples of when human experimentation was undeniably abused for consideration when writing my paper. Especially, it made note that one of America’s most treasures heroes in Thomas Jefferson was what we would now consider unethical. This again reflects the malleability of ethical philosophies concerning human experimentation. Also, it simply gives the reader food for thought and cases them into a more impressionable state of mind for my assertion to take hold.