Linda Lou Lichtenstein

PTC 604 Communication Theory and Research

September 26, 2011

Assignment 4: Ethical Questions and Research

As researchers, we must be aware of, and follow accepted ethical policies and procedures to ensure that our research respects the rights of participants. It is also important to be aware of the history that prompted these ethical policies and procedures. As such, this paper discusses lessons learned from four unethical experiments – the Nazi Medical Experiments of 1933 to 1945, the Tuskegee Syphilis Study of 1932, the Willowbrook Study from the 1950s to the early 1970s, and the Jewish Chronic Disease Hospital Study in the 1960s. The Belmont Report, in response to these atrocities and others, is the result of a commission charged with identifying "the basic ethical principles that should underlie the conduct of biomedical and behavioral research involving human subjects," was written as a reaction to these unethical studies "to develop guidelines which should be followed to assure that such research is conducted in accordance with those principals" (Department of Health, Education, and Welfare). This paper discusses the ethical principles and guidelines found in The Belmont Report as they relate to research in PTC. Also as it relates to research in PTC, consideration is given to the level of ethical thought, as discussed in Lecture 6 (Elliot), presented in the "STC Ethical Principles for Technical Communicators" (STC) document. As well, this paper considers philosophy – the tenets of three great philosophers – John Stuart Mill's "Greatest Happiness Principle", Immanuel Kant's "The Categorical Imperative", and John Rawles' "A Theory of Justice" – and how it provides a framework for decision-making with regard to ethics in research in general and to that

in PTC in particular. On a more practical level, I suggest ways the sample adult informed consent form designed by the University of Medicine and Dentistry of New Jersey (UMDNJ) (Human Subjects Protection Program Institutional Review Boards) could be adapted to conform more closely to research in PTC. And in conclusion, ethical problems that may be encountered in my research project and my proposed resolutions are offered.

What are the lessons learned from the four unethical experiments?

There are people, even doctors, who carry on unethical work for their own self-interest or under orders from above. It would be naïve to think that all doctors live up to the Hippocratic code they take to "do no harm" when the degree of medical physician is bestowed upon them. I think it is important to recognize that unethical research occurs and to educate ourselves about ethics so that we can protect ourselves and others we may have contact with, if or when we are faced with a research-based decision. When I was an undergraduate, my Parasitology professor advised us to not heedlessly volunteer to be a participant for medical research – a warning that still resonates with me, if not more so, after learning about these unethical experiments.

As researchers we must conduct our research with integrity and honesty, we must respect an individual's autonomy, and we must work with munificence (Elliot) as discussed in this paper.

How does the Belmont Report address research in PTC?

Research in PTC involves human participants; and therefore, The Belmont Report is an appropriate resource that provides "an analytical framework that will guide the resolution of ethical problems arising from research involving human subjects" (Department of Health, Education, and Welfare). To begin, the Belmont Report clearly identifies the research done in PTC as research ("an activity designed to test an hypothesis, permit conclusions to be drawn, and thereby to develop or contribute to generalizable knowledge" (ibid)) and not practice ("provide diagnosis, preventive treatment or therapy" (ibid)).

The Belmont Report lays out three principles – Respect for Persons, Beneficence and Justice – each of which is relevant to research in PTC. The first principle, Respect for Persons, requires us as PTC researchers to acknowledge the autonomy of participants in our studies. In other words, we must respect a (rational) person's judgments and his right to act on those judgments. We must not withhold information that would prevent him from making those judgments. In a more practical sense, we must fully disclose, in a clear and organized manner, our own and the participant's roles and responsibilities in the study. Based upon that disclosure we must answer questions truthfully and respect a participant's decision to participate, or to continue in the study; in essence, participation is voluntary based upon adequate and comprehensible information. The second principle, Beneficence, obligates us to secure the well-being of participants in our study in two ways: "do no harm" and "maximize possible benefits and minimize possible harms" (ibid). Although these two concepts are most commonly associated with the medical profession, they can be applied to PTC research as well. As researchers, we must consider the welfare of, and be sensitive to the emotions of our participants both during the design and the execution of our study; we must make each participant as comfortable as possible including providing breaks and avoiding undue stress. The third

principle, Justice, posits that "equals ought to be treated equally" (ibid). To the PTC researcher, this means that each participant is treated in a like manner to all other participants. Each participant is given the same information upon which to decide whether to enter the study. Each participant is given the same treatment while participating in the study. And each participant is given the same consideration for confidentiality in the study documentation.

Are STC's Ethical Principles Level 1 or Level 2?

I believe that STC's Ethical Principles are Level 2. They incorporate the Level 1 principles laid out by the American Psychological Association (APA) as well as the Level 2 philosophical subjects, both as presented in Lecture 6.

Level 1 principles include Competence, Integrity, Professional and Scientific Responsibility, Respect for the Rights and Dignity of Others, and the Concern for the Welfare of Others, and Social Responsibility. Level 2 principles include the five subjects of philosophy – Logic, Epistemology, Aesthetics, and Ethics. Parallels can be made between Level 1 and 2 principles and STC's Ethical Principles. The principle of Competence ("be aware of our own competence…our own boundaries and particular competencies and limitations" (Elliot)) is recognized under the STC subtitle 'Professionalism' whereby we 'seek definitive assessments of our own professional performance … and we also pursue professional self-improvement, especially through courses and conferences" (STC) and correlates with the philosophical principle of Epistemology (the study of knowledge). The principle of Integrity ("what we do should be honest, fair, and respectful of others" (Elliot) is peppered throughout the STC Ethical Principles under the subtitles of Honesty ("To the best of our ability, we provide truthful and

accurate communications"), Confidentiality ("We respect the confidentiality of our clients, employers, and professional organizations"), and Fairness ("We respect the cultural variety and other aspects of diversity in our clients, employers, development teams, and audiences"); it correlates with the philosophical principle of Ethics ("the nature of the good, the proper, the virtuous" (Elliot). The principle of Professional and Scientific Responsibility whereby we recognize that responsibility "for ourselves and for others to cooperate with other professions or other institutions to seek out information" (Elliot) is referred to in the STC Principles on a professional level more so than on a scientific level. The STC Principles provide guidance concerning cooperation with others under the Honesty subtitle ("Before using another person's work, we obtain permission…", and Confidentiality subtitle whereby "we obtain releases from clients and employers before including any business-sensitive materials" in our own work, as well as under the Fairness subtitle whereby we "we avoid conflicts of interests." This principle also falls under the philosophical category of Ethics; as do all of the following principles. The APA principle of Respect for the Rights and Dignity of Others refers to autonomy from both a legal and ethical perspective. The STC Ethical Principles provide for the legal aspect under the subtitle of Legality ("We observe the laws and regulations governing our profession") and broadly for the ethical perspective under the subtitle of Fairness ("We serve the business interests of our clients and employers as long as they are consistent with the public good"). The guidelines under the STC subtitle of Fairness also applies to the APA Principle of Concern for the Welfare of Others, or munificence, that is, "the means of doing good" (Elliot). Finally, Social Responsibility whereby "we are called as researchers into the service of others" (Elliot) is the main crux behind the STC Ethical Principles and is relevant to each of the subtitles.

Summarize the essence of Utiliatrianism, Kantianism, and Social Justice Theory

Utiliatrianism

Utilitarianism as put forth by John Stuart Mill in his Greatest Happiness Principle is stated as "The Ultimate End, with reference to and for the sake of which all things are desirable (whether we are considering our own good or that of other people), is an existence exempt as far as possible from pain, and as rich as possible in enjoyments" (Elliot). According to Brink, "Utilitarianism was a progressive doctrine historically, principally because of its *universal scope* — its insistence that everyone's happiness matters — and its *egalitarian conception of impartiality* — its insistence that everyone's happiness matters equally. …Utilitarianism, in its most general form, claims that one should assess persons, actions, and institutions by how well they promote human (or perhaps sentient) happiness." As such, it provides a moral guidepost for "distinguishing right and wrong…actions are right in proportion as they tend to promote happiness; wrong as they tend to produce the reverse of happiness" (Heydt) whereby "happiness is intended pleasure and the absence of pain; by unhappiness, pain and the privation of pleasure" (Heydt).

Kantianism

In Grounding for the Metaphysics of Morals (1785), Immanuel Kant proposed The Categorical Imperative which stated, "Act only according to that maxim by which you can at the same time will [desire] that it should become a universal law" (Elliot). We should not undertake an action unless we can imagine it as being a matter of policy whereby it can be undertaken repeatedly under similar circumstances (Elliot). According to McCormick, Kant is telling us that the morality of our actions is not whether we achieve what we intended by our actions (because

it is frequently out of our control); but rather, the will behind our action (because "we can will to act according to one law rather than another").

Theory of Justice

The Original Position of John Rawles A Theory of Justice calls for "justice as fairness… we are to imagine ourselves in the position of free and equal persons who jointly agree upon and commit themselves to principles of social and political justice" (Freeman). To achieve such "impartiality of judgment" (ibid), Rawles proposes a 'Veil of Ignorance' whereby all persons involved have no knowledge of "personal characteristics ('preferences, likes or dislikes, commitments or aversions' (Richardson)) and social ('place in society' (Elliot)) and historical circumstances" (ibid). In this way, all persons are on the same level, no one person has more power than any other.

Which do I think is most useful in providing a decision-making framework for PTC research?

I think that Kantianism is most useful in providing a decision-making framework for us as PTC researchers because it advocates that we undertake actions as we imagine them policy; in this regard, we act according to the ethical guidelines set forth by our profession.

Adult informed consent form – how would I adapt it to my own research?

As written, I found the UMDNJ IBR consent form to be a bit scary and very clinical. Overall, I would adapt it to my research by presenting it with nonintimidating language. A copy

of the modified consent form is in the Appendix of this paper, and a copy, with revisions noted, is uploaded to Assignment 4 in addition to this paper.

The adaptations I would make are as follows:

- Remove all references to medical procedures, drugs, tissue and blood samples.
- Change all references (in the version to be signed) to the word ‘subject’ to ‘participant’ and, all references to the study researcher as ‘doctor’ to me as ‘investigator.’
- Indicate that every effort will be made to make the participant comfortable. I am uncomfortable with the terminology in the question about risks and discomforts, and benefits.
- Modify the question concerning confidentiality of information to say that information will be kept confidential because the participant will only be identified by a number on the data collection sheets.
- Indicate whether the participant will be videotaped or not.

Potential ethical problems for my research and their resolutions

Some potential ethical problems that could arise and their resolutions include:

- Information gathered not kept confidential – I will not associate names with the data at the time of collection or in the write up; instead, I will refer to participants by number.

- Information given to each participant varies – In order to ensure that each participant is given the same information about the study, I will create a script with the information I want to convey. I will read from that script when explaining the study to participants. Where possible, I will convey the information in groups of participants rather than individually.
- Study parameters not understood by participants – I will try to explain the study as completely and clearly as possible, and will be open to any questions. I will try to answer questions to the satisfaction of the participant who asked it. I will ensure that the participants know that their involvement with the study is voluntary and that they can quit at any time.
- Well being of participants not respected – I will allow participants to take breaks as needed. I will stay tuned in to the participants emotions and provide support, as needed. I will design the study so that I will not ask personal or probing questions that are not necessary for the study. If a participant does not want to answer a question, I will not require him to answer.
- Ethical principles not followed – I will follow the ethical guidelines laid out for us as PTC research professionals.

Appendix

Modified Sample Adult Informed Consent Form

INVESTIGATOR INSTRUCTIONS ARE IN ITALICS – THE INSTRUCTIONS ARE INCLUDED TO ASSIST IN YOUR SUBMISSION AND MUST BE DELETED PRIOR TO SUBMISSION

YOU CAN USE I OR YOU (First or Second Person) LANGUAGE-BUT, BE CONSISTENT

CONSENT TO TAKE PART IN A RESEARCH STUDY

TITLE OF STUDY: (*ADD THE TITLE OF THE STUDY HERE)*

This consent form is part of an informed consent process for a research study and it will give information that will help you to decide whether you wish to volunteer for this research study. It will help you to understand what the study is about and what will happen in the course of the study.

If you have questions at any time during the research study, you should feel free to ask them and should expect to be given answers that you completely understand.

After all of your questions have been answered, if you still wish to take part in the study, you will be asked to sign this informed consent form.

The study investigator will also be asked to sign this informed consent. You will be given a copy of the signed consent form to keep.

You are not giving up any of your legal rights by volunteering for this research study or by signing this consent form.

Why is this study being done?

EXPLAIN IN PLAIN LANGUAGE THE PURPOSE OF THE STUDY. LIMIT SENTENCES TO TWELVE WORDS (OR FEWER) WHERE POSSIBLE.

Why have you been asked to take part in this study?

EXPLAIN IN PLAIN LANGUAGE WHY THE SUBJECT IS BEING INVITED TO TAKE PART IN THE STUDY. LIMIT SENTENCES TO TWELVE WORDS (OR FEWER) WHERE POSSIBLE.

Who may take part in this study? And who may not?

CLEARLY DESCRIBE INCLUSION AND EXCLUSION CRITERIA IN PLAIN LANGUAGE-DESCRIBE ONLY THOSE CONDITIONS THAT THE RESEARCH SUBJECTS WOULD BE EXPECTED TO UNDERSTAND.

How long will the study take and how many individuals will participate?

EXPLAIN IN PLAIN LANGUAGE HOW MANY SUBJECTS WILL PARTICIPATE IN THIS STUDY AND THE DURATION OF PARTICIPATION.

Will there be breaks during the study session?

Indicate the schedule of the study and that participants can take breaks as needed.

Will the study session be videotaped?

Indicate if the study session will be videotaped or not.

Will there be any cost to you to take part in this study?

EXPLAIN IN PLAIN LANGUAGE WHAT THE COST TO PARTICIPATE WILL BE, IF ANY.

Will you be paid to take part in this study?

CLEARLY OUTLINE WHAT WILL HAPPEN

How will information about you be kept private or confidential?

(INSERT A DESCRIPTION OF HOW RECORDS AND DATA WILL BE STORED AND MAINTAINED AND WHO WILL HAVE ACCESS. DESCRIBE ANY STUDY SPECIFIC ISSUES THAT MAY INCREASE THE RISK OF BREACH OF CONFIDENTIALITY.)
Indicate that the participants name will not be associated with the data during data collection, but rather a number will be used for identification purposes.

What will happen if you do not wish to take part in the study or if you later decide not to stay in the study?

You may choose not to be in the study. If you do choose to take part it is voluntary. You may refuse to take part or may change your mind at any time.

If you do not want to enter the study or decide to pull out of the study, your relationship with the study staff will not change, and you may do so without penalty and without loss of benefits to which you are otherwise entitled.

Who can you call if you have any questions?

If you have any questions about taking part in this study, you can call the study investigator:

EXAMPLE: *Study Investigator*
973-*Contact Number*
Email address

What are your rights if you decide to take part in this research study?

You have the right to ask questions about any part of the study at any time. You should not sign this form unless you have had a chance to ask questions and have been given answers to all of your questions.

Do I have to sign this authorization form?

You do not have to sign this authorization form. But if you do not, you will not be able to participate in this research study.

If I sign, can I revoke my authorization or withdraw my information later?

If you decide to participate, you are free to withdraw your authorization regarding the use and disclosure of your information (and to discontinue any other participation in the study) at any time. After any revocation, your information will no longer be used or disclosed in the study.

If you wish to revoke your authorization for the research use or disclosure of your information in this study, you may do so in writing by contacting *(investigator's name, address, and contact information).*

What personal information will be used?

Your information related to this study, may be used or disclosed in connection with this research study, including, but not limited to, (*List or describe any and all information collected from or about the subject in connection with this study.)*

Who may use the information?

The following parties are authorized to use and/or disclose your information in connection with this research study:

Linda Lou Lichtenstein

Who may receive/use the information?

The parties listed in the preceding paragraph may disclose your information to the following persons and organizations for their use in connection with this research study:

None

AGREEMENT TO PARTICIPATE

I have read this entire form, or it has been read to me, and I believe that I understand what has been discussed. All of my questions about this form or this study have been answered.

Participant Name:_____

Participant Signature:_____ Date:_____

Signature of Investigator/Individual Obtaining Consent:

To the best of my ability, I have explained and discussed the full contents of the study including all of the information contained in this consent form. All questions of the research participant and those of his/her parent or legal guardian have been accurately answered.

Investigator/Person Obtaining Consent:_____

Signature:_____ Date: _____

References

Brink, David. *Mill's Moral and Political Philosophy*. *Stanford Encyclopedia of Philosophy*. 9 Oct 2007. Web. 25 Sept 2011.

Courage, Catherine, and Kathy Baxter. *Understanding Your Users: A Practical Guide to User Requirements Methods, Tools, & Techniques*. China: Elsevier, 2005. Print.

Department of Health, Education, and Welfare. *The Belmont Report: Ethical Principles and Guidelines for the protection of human subjects of research*. *National Institutes of Health Office of Human Subjects Research*. Web. 23 Sept 2011.

Elliot, Norbert. "Lecture 6 – Ethical Questions and Research: A Guide to Philosophical Decision-Making." Professional and Technical Communication Podcast Lecture Series for PTC 604. New Jersey Institute of Technology. 23 Sept 2011.

Freeman, Samuel. *Original Position*. *Stanford Encyclopedia of Philosophy*. 20 Dec 2008. Web. 25 Sept 2011.

Heydt, Colin. *John Stuart Mill (1806 – 1873). Internet Encyclopedia of Philosophy*. 24 Oct 2006. Web. 25 Sept 2011.

Human Subjects Protection Program Institutional Review Boards. "Adult Consent Form Template". *IRB Consent Form Templates*. UMDNJ University of Medicine and Dentistry of New Jersey. Web. 23 Sept 2011.

McCormick, Matt. *Immanuel Kant: Metaphysics*. *Internet Encyclopedia of Philosophy.*17 Apr 2001. Web, 25 Sept 2011.

Richardson, Henry S. *John Rawles (1921 – 2002). Internet Encyclopedia of Philosophy*. 18 Nov 2005. Web. 25 Sept 2011.

STC. STC *Ethical Principles for Technical Communication*. Sept 1998. Web. 23 Sept 2011.

Williams, Garrath. *Kant's Account of Reason*. *Stanford Encyclopedia of Philosophy*. 12 May 2009. Web. 25 Sept 2011.