“You Want to Do What with Whom?” The Practice of Human Research Ethics

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In 1963, Yale University researcher, Stanley Milgram, devised an experiment to test the conditions under which human participants would obey commands that contradicted their own ethical standards. He had participants pair up and perform a draw to determine who would ask a series of questions and who would answer them. The draw was rigged, however, because those who would be answering were plants, allies of the researcher.

The participants asking the questions were told that this was an experiment to test the role of punishment in learning. They were to ask a question. If the answer was wrong, they were to administer an electric shock by pressing one of a number of buttons. The buttons delivered from 15 to 450 volts. The participants were told that the shocks would be painful but would do no permanent damage. Each wrong answer would lead to a shock of increasing voltage.

Under strong urging from the researcher, and in a condition in which answers were consistently wrong, all participants increased the shock level to 300 volts, at which time the person answering cried out, asked loudly to be allowed to stop, and pounded on the wall. The majority of the participants continued to 450 volts, even though the person answering no longer responded at all (Milgram, 1963).

In fact, there were no electric shocks. The experiment had been staged. Participants didn’t know this, however, and experienced extreme stress. What is more, for those who wanted to end the experiment, they were told that they must continue, thus being deprived of their right to withdraw. While we don’t know how participants fared in the days, weeks, and months after the experiment, it is likely that there were ongoing effects even though they had been debriefed and told about the deception.

Milgram continued with many more such experiments over several years. Today a research ethics board would likely have prevented him from doing so, but in that era there were no such boards. In the interests of science, Milgram justified his violation of participant rights.

Do We Need Human Research Ethics Boards?

The Milgram experiments were an extreme. Ordinary, ethical researchers would never go as far as he did. If that is the case, do we need ethical review? Published research has gone through a process of peer review which surely investigates research ethics and refuses to publish the products of unethical research. At least, that is what we would hope.

The problem is that peer review as part of journal article publication happens after the human participants study is over. By that time it is too late to protect the participants. And there is no assurance that a researcher, seeing a higher good in pursuing a line of research, won’t violate participants’ rights and justify it with the value of the resulting data.

The essence of our trust in the results of research is our belief that the research was done within ethical standards. At the extreme ends we have the Nazi experiments which may, indeed, have found some useful data related, say, to the effect of extreme cold on the human body. But, when tainted with huge violations of ethical principles, the research itself is a product of criminal activity.
What Does Ethics Approval Accomplish?

There are a few cornerstones to Human Participant Human Research Ethics:

1. Is the consent of participants free and sufficiently informed? Here there are a number of factors:

   a. Freedom of Consent

   If participants are in some way coerced into participating or compelled to continue when they would rather withdraw (as happened in Milgram’s experiments), their rights are violated. Some of the factors that we need to consider are power over (Is the researcher able to bring negative consequences to bear if a participant refuses to be involved?), or some other sense of obligation to participate. Participants must voluntarily agree to involvement and know that they have the option to withdraw consent at any time, or their rights are being violated.

   Another factor here is that participants who believe they are being coerced may well provide skewed data in accord with what they believe the researcher wants to hear rather than what they truly believe. So it is in the best interests of researchers to remove all coercion.

   b. Informed Consent

   The principle here is that participants need to have a clear idea of what they are getting into so that there are no surprises once they agree to participate. A big challenge here is that deception is sometimes allowed in order to further the goals of research. For example, you may have a researcher pretend to have a disability and fall to measure some aspect of the public’s readiness to help a stranger. Such studies don’t even provide for consent from participants, let alone informed consent, but the goal of the research will sometimes have research ethics boards approving them anyway.

   What is key here is that informed consent is the rule and deception must be rare. If there is deception, it must do no perceived harm to the participant. In my own experience, I find deception of any sort troublesome. As an evaluator of research ethics proposals, any planned deception gets much more scrutiny than more straightforward studies.

   Again, deception can lead to skewed data. This can happen if a participant figures out the deception or if the deceptive situation takes a participant out of his or her normal field of behavior and thought. Deception moves participants into artificial territory, and you cannot be sure that the deception parameters are actually measuring what you want to measure.

   c. Do no harm

   Participants are volunteers, drawn out of a sincere desire to contribute to research. They expect to be treated well. If there are any perceived risks, those have to be spelled out in the consent document so that participants know what those risks are. Milgram’s experiments are great examples of participants having no idea how very damaging his experiment would be to them. If you watch any of the videos (McLeod, 2007) of participants in his experiments, you see signs of extreme and seemingly unexpected distress.
Some participants are members of vulnerable populations, and great care must be taken to limit harm to them. These might include people limited mental or physical capacity, children, or those who have experienced loss or trauma that might trigger extreme emotions. It is the duty of human research ethics boards to offer special consideration to such populations while at the same time preserving their right to participate. This can be a difficult task when it is clear that their participation could produce some measure of challenge or even harm to them.

Over the history of research, experiments that did much harm to participants abound (Wrigley, 2015, June 8). A sound research ethics evaluation will root out those studies that intend or would lead to harm needlessly. In cases where there is higher risk, participants need to make their decisions about involvement on the basis of sound understanding of the risks they face.

How Do We Determine What is Ethical?

Anyone who has studied ethics in any field knows that ethical issues are among the most complicated to unravel. We may have rules to live by, but individual circumstances can violate those rules and still be ethical. If someone, for example, ran into this room firing a gun, I would be within proper ethical boundaries to attack that person, even injuring or killing him. The need to preserve the life of the group in that case stands higher than the need to preserve the life of someone intending to harm the group.

All ethical decisions involve weighing rights and responsibilities. Some ethical challenges are easy to solve, but some are exceedingly difficult. A strict rules-based ethical system can actually do more harm than good if human ethics reviewers argue that they followed the rules and yet ignored special circumstances.

Thus you will find that most ethical systems in human research ethics are sets of guidelines that establish ethical principles rather than hard and fast rules. The one document that most governs our ethical research efforts in Canada is TCPS 2 (2014) - Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (Panel on Research Ethics, 2014), created under the auspices of the three main federal research grant funding organizations. All universities and many other research bodies in Canada are obligated to utilize this policy in their own human research ethics boards. The policy is a set of guidelines intended to ensure that research is ethical within all bodies that do research.

From here, the real challenge begins. Each research proposal carries its own ethical issues, some of them minor and some of them spectacular. Should we allow research in a high school among students who are regularly cutting themselves? Should researchers be allowed to meet with suspected terrorists to determine their views? Should we allow the interviewing of recently bereaved parents regarding their experience with the grief process? A yes or a no often comes after much investigation and much discussion.

What Do the Researcher and the Institution Gain from Research Ethics Evaluation?

Some researchers find ethics review onerous. They know that they will strive to be ethical, so why go through all these hoops? There are several reasons why ethics review is good for the researcher:

1. Ethics review allows an independent assessment. A researcher may well believe a study is ethical, but anyone can miss things that an ethics reviewer would more easily notice.
Inadvertently doing something unethical is as much of a problem as doing it on purpose, since both bring harm or rights violations to participants.

2. Ethics review offers some measure of protection to the researcher and the researcher’s institution. Ethics review is an exercise of due diligence that flags ethics problems and seeks to ensure that any issues raised later by participants are minimized. If researchers cannot show that the ethics of the study have been reviewed, potential accusers have more ammunition to argue that they were not treated fairly. The researcher’s institution could risk a lawsuit.

3. Ethics review is crucial if a researcher wants to publish or to get grades for a course. Without ethics review, the research is suspect and will not find a wider venue. Professors will not accept student research without review.

Conclusion
The field of Human Research Ethics is a developing one. While those who set guidelines or do reviews are not flawless, we are moving closer and closer to research that violates no participant and results in data that we can share with pride.

Link to Google Slides presentation: https://docs.google.com/presentation/d/183-j9uyPYzwNr5xRxy9ZCJ4Pjw7Tjfmvsblo2FQJJqo/edit?usp=sharing

References

