When Research Serves Good Purposes: Three Additional Considerations to Determine the Ethical Use of Ill-Gotten Research

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INTRODUCTION

It is a classic ethical dilemma to have something of potential value that comes at a tremendous cost to others.[1] To access the good, you must have the bad. For decision-makers, it becomes an onerous task of deciding if they would deny the world something 'good' or create something bad to achieve the good. Weighing the two possible outcomes has proven timelessly frustrating to those well-intentioned people who wish to "do the right thing." Medical research has yielded data derived from unethical situations wherein research participants were vulnerable and whose consent was questionable, absent, or not sought. The rules currently governing research allow for broad use of ill-gotten data. While providing a deterrent to unethical research practices, stricter rules still would allow some use of data. This paper argues the permissibility depends primarily on the nature of the unethical data collection and the potential benefits.

ANALYSIS

The American Medical Association (AMA) places additional obligations on researchers who utilize data obtained from unethical experiments. *The Code of Medical Ethics Opinion 7.2.2*[2] recommends that researchers and peer reviewers should take the following steps to best handle such data:

> *(a) Disclose that the data derived from studies do not meet contemporary standards for the ethical conduct of research.*
>
> *(b) Clearly describe and acknowledge the unethical nature of the experiment(s) from which the data are derived.*
>
> *(c) Provide ethically compelling reasons for which the data are being released or cited, such as the need to save human lives when no other relevant data are available.*
>
> *(d) Pay respect to those who were the victims of the unethical experimentation.*

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The AMA does not go far enough to protect past research victims or prevent future research ethics violations. Three additional considerations beyond the limitations offered by the APA are needed for ethical use of the data: who collected the data and ran the experiments, who would benefit from the data, and how much additional benefit would ensue from its use. A specific focus on data generated by Nazis whose research subjects were imprisoned in concentration camps highlights the ethical challenge.

I. Who Created the Data?

Medical research generated during the Holocaust subjected innocent people to torture in the name of science. Arguments can be made against the use of such data on the grounds that using the data represents a further indignity to those who suffered such horrific conditions and persecution. However, some of the data that emerged out of the Holocaust was not created by oppressors at the expense of the oppressed. Rather it grew out of the horrific conditions and was amassed by fellow prisoners. One prominent example is Myron Winick's work on hunger and disease, which edited the detailed records of Jewish physicians working in the Warsaw Ghetto, who traced the progression of starvation in stunning detail.[3]

One obvious difference is that the Jewish physicians were not responsible for the conditions under which the data was gathered. But if we ask ourselves if their work represents a further indignity to those who had their starvation documented, the answer is not so clear. In this way, it is important to determine the explicit purpose of medical research as opposed to data generation as one aspect of the violation. To record the medical symptoms of a 'subject' who is, as you are, a victim of the circumstances with no other recourse, is different in kind from 'subjecting' a person to the condition in the first instance. Therefore, an analysis of the person doing the research provides an added limitation on using research performed by an oppressor yet allows some lenience for research by fellow victims. Research performed by oppressors must have a significantly higher marginal benefit over other available or collectable data.

II. Who Gains from the Data? Is it of Sufficient Benefit? (An effort to expand part C of the AMA unethical experimentation rules)

In the spirit of contrition and commitment to the truth of historical ignominies, such as the Holocaust, the AMA created these best practices for physicians dealing with any ill-gotten data. In the case of the Holocaust, the period that has passed since 1945 would suggest that most, if not all, perpetrators of this research are deceased. However, prior to using data, modern researchers should ensure that there is no gain to be had on the part of the families of the perpetrators. When a large organization can offer *mea culpa* and seemingly genuine pledges toward reconciliation while still enjoying the advantages gained over others by virtue of their wrongdoing, it undermines sincerity, creates an incentive for more researchers to engage in unethical data collection, and would be an injustice to the relatives of victims. This matter may become more relevant going forward as private ownership and patents could play a role in sustaining the fiscal or reputational benefits to those who conduct science devoid of ethics.

The Belmont Report lays out a risk-benefit equation which states that research that posed significant risks to the participants must also carry sufficient benefits to those who take risks. This element suggests two aspects that speak to the "justness" of a research project: First, a balance must be struck between potential harms and potential benefits; second, those who took risks must not be precluded from accessing the benefits of the products a successful trial would create.[4]

Researchers must evaluate whether the data is both scientifically valid and usable from a methodological point of view, but also if what the use of the data promises is sufficiently compelling to benefit the progress of science. Second, the data must refer to some aspect of human health or illness, the amelioration of which would create an empirical improvement to all social and economic classes of humanity. The social justice issues embedded in the ethical use of the data are overlooked by the AMA. While the AMA suggests saving human lives makes the use of ill-gotten data acceptable, it fails to address any effort to make up for the wrongdoing. Examples of added considerations could be the use of the research to benefit people who were research subjects or their descendants or a broader race or ethnic group that was victimized.

Examples of groups subjected to unethical research in the 20th century include Residential Schools for Aboriginal Canadians,[5] senior citizens,[6] and typically, members of socially deprived and undervalued populations.[7] The more reliable scientific data that emerged from Nazi experimentation is in the areas of hypothermia,[8] malnutrition and starvation,[9] and anatomical studies.[10] It is impossible to justify the use by the AMA criteria alone. If the research benefited relatives and descendants of Nazi prisoners or the broader marginalized community of which they belonged, its use might be considered ethical if there were no other way to obtain comparable data. The value and impact of Nazi science is minimal at this point, with much more reliable data available, but this type of transgression continues. There are modern examples of data procured in breach of ethics that still lend themselves to this question.

CONCLUSION

These suggestions would add complexity and substance to the AMA's *Code of Medical Ethics Opinion*. Beyond that scope, the considerations offered here would contribute to a stronger statement about the obligations and prohibitions in circumstances in which data was wrongfully collected. Too often, one could default to a brash 'means-to-an-ends' approach, especially when issues of funding and measured productivity come into the equation. The considerations here recognize that data gathered during the Holocaust is particularly sensitive. By eliminating any encouragement of unethical practices, a stricter test for the use of ill-gotten research is a deterrent but recognizes that sometimes the benefits call for the use of the research. The considerations also recognize that one legacy of such data is to create good in the modern-day, even as we recognize the shameful context of its creation and existence.

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