"Acres of Skin" – A Reflection on the Protections and Ethical Considerations of Prison Populations in Research

1 April 2021
CEED 4245: Ethics in Research

Sophia Idso
Graduation Year: 2021
Major: Integrative Neuroscience

As a student at Fordham, I have been fortunate to take philosophy, science, and theology courses that had a heavy focus on ethical issues, and as an aspiring medical student I have been interested specifically in the inequalities in American healthcare and research. When I think about equal access to care I think primarily about communities and groups that are underinsured and marginalized in healthcare. I think about the homeless and those who have mental illness and substance use disorders that often cannot or do not seek help. Conversely, I think about my dad who struggled with a substance use disorder for much of my life but who was able to recover because he had the help of a support system, access to care, and the opportunity to attend a treatment program. While completing a reading for my ethics class, I learned about the role of prisoners in clinical trials, and specifically some of the experiments that have used prisoners as participants. I came across the quote “acres of skin”, from Dr. Albert M. Kligman, a dermatologist involved in the Holmesberg Prison experiments, referring to what he saw when he entered the Holmesberg Prison. After reading this quote I had to take a second to reflect. I had never spent much time thinking about the prison population as a vulnerable community who may be at risk of exploitation in regards to medical research. The Holmesberg Prison experiments were non-therapeutic experiments conducted on prisoners in Philadelphia from 1951 to 1974 led by Dr. Kligman. His quote “acres of skin” used to describe *human beings* exemplifies the ways in which prisoners are seen as non-human in American culture, even by healthcare professionals who should be responsible for providing care. This attitude makes including prisoners in clinical research especially concerning.

The Belmont Report, created by the National Commision for the Protection of Human Subjects of Biomedical and Behavioral Research, outlines the basic principles that are relevant to ethical questions about research with human subjects. The first principle, which should be carefully considered in light of the attitudes I have just mentioned, is respect for persons. This principle involves respecting the autonomy of each individual participant, and protecting those who have diminished autonomy. Incarcerated persons have restricted autonomy in every aspect of their life, which puts them in a particularly vulnerable position. The prison example gives rise to several important ethical questions, including, are incarcerated persons ever able to *truly* give informed consent? And, can adequate protections *ever* be put in place to prevent situations involving coercion, exploitation, and undue risk? The second important principle from the Belmont Report that I would like to examine in this context is the principle of justice, or the considerations of possible risks and benefits being distributed equally among people. This principle brings up other important ethical questions, including, how can we ensure that the risks to incarcerated persons are not higher than the risks to the greater community? And, in practice, who will receive the benefits of the research? If prisoners were to be included in research, would the benefits of the given research be available to prisoners who may have shouldered the risks? In the Belmont Report, the application of these principles involves several steps that must be taken, including the requirement for informed consent, an attentive assessment of risks and benefits, and a careful consideration of participant selection.

The reality of the American prison system makes the questions I have outlined above even more difficult to answer. Not only is the incarcerated community already an unprotected population due to the culture and power dynamics associated with living as a prisoner, but the makeup of the American prison populations provides additional factors of vulnerability. For example, African Americans make up 40% of the American prison population but only 13% of the total US population (Gramlich, 2020). In addition, around half of prisoners have mental health concerns, and between 10-25% of inmates have a serious mental health disorder, including mood disorders or schizophrenia (Collier, 2014). Those who are incarcerated are also more likely to have a substance use disorder (an estimated 65% of prisoners have a SUD) and are less likely to have a high school diploma when compared to the greater US population ("Criminal Justice DrugFacts", 2020). Finally, salaries of incarcerated prisoners prior to their incarceration were disproportionately lower than others of the same age (Rabuy & Kopf, 2015). Discrimination due to race and ethnicity, lack of access to quality jobs and experiences of poverty, lack of education, as well as high rates of substance use disorders and mental health disorders all place prisoners in an especially vulnerable position. All of these considerations make the criteria outlined by the Belmont Report nearly impossible to achieve.

In a further analysis of prisoners participating in research, it is important to consider *why* prisoners would choose to participate, including what motivating factors, internal and external, affect their decision-making. A study by Christopher et al. articulated the main motivating factors for and against prisoners deciding whether or not to participate in research. Among the internal factors favoring participation were desire for treatment, compensation, and avoidance of an unwanted outcome; the two external factors favoring participation were constrained options and desire for humane treatment (Christopher et al., 2017). While reading this study the factor that stood out to me the most was the desire for humane treatment – incarcerated persons are often treated by staff, outside communities, and even medical professionals who are tasked with providing care within prisons as less human because of their sentence. How can research that aims at ensuring participants as whole persons with – albeit diminished – autonomy, expected to be conducted in an environment where incarcerated persons are treated as less than human every day? Furthermore, the most common internal factor favoring participation was desire for treatment. The Belmont Report carefully distinguishes the difference between "practice", which is defined as “interventions that are designed solely to enhance the well-being of an individual patient or client and that have a reasonable expectation of success” and research, which is concerned with testing a hypothesis (“Belmont Report”, 1979). This distinction is one that is often misunderstood, even outside of the prison context. Prisoners’ main reason for participating in research is the desire to have access to quality medical care – however, research is not the same as having access to care, and these studies are in essence experimental, meaning they are not designed to ensure success in the same way that practice would be. Additionally, compensation was another main motivating factor, which is one of the most obvious sources of exploitation and coercion in research involving prisoners. The Holmesberg experiments paid prisoners up to hundreds of dollars to put themselves at risk through experiments with radioactive materials, carcinogens, and more toxic substances. Possibly the most shocking part of these experiments was that prisoners could end their sentences if they were able to pay 10% of their bail amount -- which could often be achieved by participating in these experiments -- but researchers such as Dr. Kligman maintained that the inmates were not unduly coerced to participate (Hornblum,1999). While situations as extreme as this one may not happen today, these experiments bring up important examples of coercion that must be addressed. If prisoners do not have access to even minimum-wage jobs within the prison, how can researchers ensure that compensation will not persuade prisoners to participate and possibly impact the informed consent that they can give? Even if payments are small by an outsider’s standards, prisoners may still be swayed to give consent to research based solely on the lack of opportunity for paid work within a prison.

Research with incarcerated persons is a complex and difficult ethical topic, not only because of the obvious ethical considerations, such as diminished autonomy and possible coercion, but also because of the underlying attitudes about prisoners in American culture. Because incarcerated individuals are part of the greater American society, we have an obligation to consider how research that we want to conduct may disproportionately and adversely affect these incarcerated persons, if they are allowed to participate. If we begin by treating prisoners as “acres of skin”, through our attitudes and considerations, can we ever be sure that incarcerated persons will be appropriately protected in research?

Works Cited

THE BELMONT REPORT ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH [PDF]. (1979, April 18). The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.

Christopher, P. P., Garcia-Sampson, L. G., Stein, M., Johnson, J., Rich, J., & Lidz, C. (2017). Enrolling in Clinical Research While Incarcerated: What Influences Participants' Decisions? *Hastings Center Report*, *47*(2), 21-29. doi:10.1002/hast.686

Collier, L. (2014, October). Incarceration nation. Retrieved March 30, 2021, from https://www.apa.org/monitor/2014/10/incarceration

Criminal justice drugfacts. (2020, June). Retrieved March 30, 2021, from https://www.drugabuse.gov/publications/drugfacts/criminal-justice

Gramlich, J. (2020, August 06). Black imprisonment rate in the U.S. has fallen by a third since 2006. Retrieved March 30, 2021, from https://www.pewresearch.org/fact-tank/2020/05/06/share-of-black-white-hispanic-americans-in-prison-2018-vs-2006/

Harlow, C. W. (2003, January). *Education and Correctional Populations* [PDF]. U.S. Department of Justice.

Hornblum, A. M. (1999). *Acres of skin: Human experiments at Holmesburg Prison; a true story of abuse and exploitation in the name of medical science*. London: Routledge.

Rabuy, B., & Kopf, D. (2015, July 9). Prisons of poverty: Uncovering the pre-incarceration incomes of the imprisoned. Retrieved March 30, 2021, from https://www.prisonpolicy.org/reports/income.html

Urbina, I. (2006, August 13). Panel suggests using inmates in drug trials. Retrieved March 30, 2021, from https://www.nytimes.com/2006/08/13/us/13inmates.html