

February 22, 2018

Chynn Prize in Ethics and Morality Essay

On Protecting the Agency of Undocumented Immigrants from Patterns of Our Past

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FCRH 2018

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Ethics in Research, PYSC/SOCI/CEED 4245

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Spring 2018

In the history of the United States rhetoric alienating immigrants, documented and undocumented, has consistently pervaded everyday life across the nation, from the front page of *The New York Times* to college campuses to airports to Congressional hearings to, indeed, even research. While I myself am not an immigrant, my family has a history of immigration and can trace our family's name on the stones of Ellis Island and in the Federal Register of U.S. Citizenship. Understanding and celebrating my family's heritage and the particular journeys that led both of my grandparents to America was a large part of my childhood and formative for my identity.

Thus, such conversations at home also prompted an awareness for the current experience of undocumented immigrants in today's American society since it was an issue that had come to the fore of national discourse during my time growing up and attending public schools. While the experiences have certainly changed, the vulnerability of immigrants (documented or not) remains. As the topic of immigration has become more and more polarized and remains constant in headlines, a notable vulnerability of undocumented immigrants lies in the dangers of unethical research. At a time when contemporary research involving undocumented immigrants is undoubtedly in the interest of the public and the immigrants themselves, there are stark ethical questions that must be addressed. The main ethical question we are faced with is how can we protect the fragile balance of vulnerability that lies with undocumented immigrants' participation in research while also effectively producing valid and ethical research that is productive to society. The answer to such a far-reaching question lies in an understanding and enforcement of ethical research paradigms sensitive to the involvement of undocumented immigrants such as confidentiality, consent, and cross-cultural barriers. Through isolating the ways in which aspects of research like confidentiality, consent, and cross-cultural barriers have been used unethically in

the past against undocumented immigrants, only then can we understand our moral obligation to shielding individuals from such immoral treatment in the future.

Accounts of the struggles my grandparents faced with respect to education, language, and basic cultural norms and practices, as well as accounts that exist for centuries back in American archives, detail many of the cultural barriers and myriad of challenges immigrants encounter. It is through this window we are provided glimpses into the ways immigrants face constant threats to their agency as they endeavor to weave their way into the social fabric of American society. These cultural tensions pose an easy threat to ethical research in that such factors stand in the way of full understandings of participation in research; and perhaps it is my own family's past that prompts me to feel an obligation to understanding and advocating for the agency of all immigrants. But it should be more than just a personal connection that prompts action, for immigration has arguably made our country what it is today and continues to do so. Thus, we can no longer use the excuse of cross-cultural barriers to allow for unethical treatment of individuals, instead we need to combat it through providing sufficient education and resources to aid the immigrants with tools to defend themselves from exploitation.

The Belmont Report which is the product of The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research of April 18, 1979 details ethical principles and guidelines for the protection of human subjects of research and serves as one of

these resources. It states as a basic ethical principle “Respect for Persons”¹ being that “the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy.”² Undocumented immigrants face a conflicting status as autonomous individuals, but also their legal status places them in the precarious position of temporary vulnerability and diminished autonomy due to the increased potential for exploitation. The Belmont Report lists “circumstances that severely restrict liberty”³— as are indeed the conditions one operates under as an undocumented immigrant— to be a restricting factor of a person’s autonomy and capacity for self-determination. And so as fully operating autonomous individuals in American society, I believe that those who can do have a responsibility to protect the agency that remains still available to undocumented immigrants despite facing the barriers they face. This responsibility should not be regulated to simply being good neighbors, but ensuring that the rights we enjoy are extended to them as well.

Further, the report states that “respect for persons demands that subjects enter into the research voluntarily and with adequate information”⁴ the application of this principle is detailed in the report’s guidelines for Informed Consent. Informed Consent requires that subjects are in

¹ *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. N.p.: [Washington, DC]: Dept. of Health Education, and Welfare, April 1979., 1979, 4.

² *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*, 1979, 4.

³ *Ibid*, 4.

⁴ *Ibid*, 5.

full knowledge and understanding of their opportunity to participate and “to choose what shall or shall not happen to them.”⁵ As a result of atrocities committed by Nazi doctors and other unethical research that has taken place, such as the Tuskegee Syphilis Study, the international community has responded with doctrines like the Nuremberg Code (1946), The Belmont Report (1979), and the American Psychological Association’s (APA) ethical standards for research (2002) to safeguard research and set guidelines for work. Undocumented immigrants face a specific set of risks in that they have much to lose and little to gain from the risks posed by research should obstacles arise or should researchers choose to be unethical in their implementation of procedures. In this way, “failure to properly implement informed consent procedures involving vulnerable populations can harm participants and their communities and diminish public trust”⁶ which threatens not just the illegal aliens but the research world as a whole. An integral part of Informed Consent is full disclosure of things such as “what information will be kept confidential, the methods employed to maintain confidentiality, and the legal, social, and professional standards requiring disclosure of confidential information.”⁷ Confidentiality is arguably the most important aspect of Informed Consent for immigrants in that the undocumented immigrant must fully understand what is at risk: potentially their livelihood in

⁵ Ibid, 6.

⁶ Adam L. Fried and Celia B. Fisher. “The Ethics of Informed Consent for Research in Clinical and Abnormal Psychology.” *Handbook of Research methods in abnormal and clinical psychology*, ed. D.Mckay: Sage Publications, 2008, 5.

⁷ Adam L. Fried and Celia B. Fisher. “The Ethics of Informed Consent for Research in Clinical and Abnormal Psychology”, 7.

on foreign soil. The language used when discussing Confidentiality is also where unethical behavior can take place in that if it is too confusing or incomprehensible for the subject it can lead to coercion to opt in out of fear or pressure.

These factors are the most pertinent to the plight of undocumented immigrants as part of their limited autonomy stems from a lack of understanding and capability to communicate this lack of understanding due to often extenuating circumstances which grow out of cultural barriers; and unfortunately often unethical disdain for their agency on the part of the researchers. Often unethical coercive compensation incentives and even threats of deportation can be chalked up to lack of proper informed consent and unethical implementation of procedures. Thus, illegal aliens who find themselves potentially participating in research must place a large amount of trust in a system and the IRB review to shield them and protect their rights, interests, and their compromised status. It is also on the public, I believe, to take special care and pay attention during such a sensitive time for the relationship between immigrants, our nation, and research.

Therefore, while this examination only touches upon the surface of the intricacies of ethical research when dealing with undocumented immigrants it is important to remember the moral responsibility of the researcher to act with ethical intentions and to treat their subjects—regardless of their legal status—with the respect and dignity their human agency demands. For the implications, and merely the intent, of unethical treatment of such human subjects in research poses a threat not just to the research and the subject, but perhaps more

importantly the collective memory of the immigrants who came before and the immigrants who will come after.

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