THE MYTH OF INFORMED CONSENT: AN ANALYSIS OF THE DOCTRINE OF INFORMED CONSENT AND ITS (MIS)APPLICATION IN HIV EXPERIMENTS ON PREGNANT WOMEN IN DEVELOPING COUNTRIES

JAY DYCKMAN[*]

INTRODUCTION

It has been just over fifty years since Nazi Germany taught the modern world the vicious consequences of utilizing politics and fascist ideology to shape and direct science, medicine, and health care. The horrific experiments and medical rationing conducted by the Nazi government fractured the idea that science and medicine aim to care for and protect the body, and exposed how politics necessarily drives decisions as to which "bodies" are worthy of protection. By constructing the Jew's body as inherently inferior to the model Aryan physique, German doctors and scientists were able to create a justification for withheld care, coerced medical experimentation, and the final solution of annihilation. The legacy of these atrocities was a post-war declaration of the intrinsic uniqueness of each individual and the sacredness of each body. Called the Nuremberg Code, this document provides guidance to those in the medical field by structuring a means to achieve the goal of securing the bodily integrity of each human subject.[1] The principle vehicle of the declaration is the doctrine of informed consent.

---

[*] Law Clerk to Judge Nina Gershon, U.S. District Court, Eastern District of New York; J.D., Columbia University, 1999; B.A., Princeton University, 1995. I am very grateful to my family and friends for their useful comments and support, the *Columbia Journal of Gender and Law* for its editorial assistance, and Professor Patricia Williams for her encouragement and helpful suggestions on early drafts of this article.

[1] *See* 2 Trials of War Criminals Before the Nuremberg Military Tribunals Under Control Council Law No. 10, 181-82 (1946-1949).

The memory of Nazi Germany's destruction of "other" bodies weighs upon the design of any contemporary medical experiment that involves human subjects. An experiment's goals and the rationale for using human subjects should always be constrained by the knowledge that political and social constructions of how certain bodies are perceived and valued distort these goals and rationales. As American health organizations fund and conduct an increasing number of experiments involving poor persons of color in developing countries,[2] understanding this perspective has become more urgent than ever. Most recently, experiments on pregnant HIV-positive women have generated controversy over the level of respect shown for the Nuremberg Code by the American health organizations conducting the tests.[3]

Since 1997, the Centers for Disease Control (CDC) and the National Institutes of Health (NIH) have paid for and conducted experiments on pregnant women infected with HIV in Thailand, the Dominican Republic, and several African nations. These studies involve more than 12,000 women in seven countries and aim to find a cheap and effective method of preventing transmission of HIV to babies.[4] Two years prior to the inception of these experiments, however, in a study conducted in France and the United States, researchers discovered that a regimen of AZT during the later stages of pregnancy can reduce the chances that the baby will be born infected with HIV by two-thirds.[5] This drug regimen costs about $1000 per woman, too expensive for these volunteers and their national health care systems. Consequently, the most recent studies hope to find a less expensive way to use AZT by reducing the amount needed to block transmission.[6]

---

[2] *See* Peter Lurie & Sidney Wolfe, Unethical Trials of Interventions to Reduce Perinatal Transmission of the Human Immunodeficiency Virus in Developing Countries, 337 New Eng. J. Med. 853, 854 (1997).

[3] *See infra* text accompanying notes 7-13.

[4] *See* Sheryl Gay Stolberg, U.S. AIDS Research Abroad Sets Off Outcry Over Ethics, NY Times, Sept. 18, 1997, at A1.

[5] *See* Susan Okie, HIV Transmission's Two Worlds; Mother-to-Baby Rates Down Here, Not in Poor Countries, Wash. Post, Sept. 16, 1997, at Z07. The regimen used in the United States requires a woman to take AZT five times a day for the last two-thirds of pregnancy and to receive the drug intravenously during labor, as well as giving AZT to her baby four times a day for six weeks. The study, known as AIDS Clinical Trial Group (ACTG) Study 076, was completed in 1994. *See* Stolberg, *supra* note 4, at A1.

[6] *See* Stolberg, *supra* note 4, at A1. One Ugandan scientist noted that the government health expenditure is three dollars per person per year, and the average citizen makes less than one dollar per day. *See* Danstan Bagenda and Philippa Musoke-Mudido, A Reaction: We're Trying to Help Our Sickest People, Not Exploit Them, Wash. Post, Sept. 28, 1997, at C03.

To achieve this goal, the CDC and NIH have designed studies which include the use of a placebo for half of the participants. It is estimated that more than 1,000 babies will contract the AIDS virus because of the placebo treatment given to their mothers.[7] Critics of the placebo studies assert that research from the French and American experiments, which proved the effectiveness of AZT for pregnant women, provides the necessary data for researchers to compare against well-designed shorter regimens without the need for a placebo.[8]

Furthermore, the use of a placebo has provoked allegations that the tests, in which potential treatment is withheld from willing test participants, are unethical. One of the most widely disseminated criticisms compared the tests to the notorious Tuskegee experiments that left many poor black men suffering from syphilis even decades after a cure was found.[9] This comparison, first published in an editorial in the influential *New England Journal of Medicine*, triggered a charged public debate not only among the journal's own editorial board but also throughout the scientific and AIDS activist communities. To be sure, the comparison to the Tuskegee experiments was intended to elicit a strong public reaction, especially considering the recent publicity surrounding President Clinton's public apology to the survivors of the Tuskegee experiment.[10]

Supporters of the tests bluntly dismissed such criticism as "calling on people's emotions rather than dealing with the facts in this case."[11] The

---

[7] *See* Stolberg, *supra* note 4, at A1.

[8] *See* Lurie & Wolfe, *supra* note 2, at 854.

[9] *See* Marcia Angell, Editorial, The Ethics of Clinical Research in the Third World, 337 New Eng. J. Med. 847, 847 (1997). Angell is the executive editor of the *New England Journal of Medicine*. Describing the Tuskegee experiments, she writes: "In 1932 the U.S. Public Health Service undertook a study of 412 black men in rural Alabama who had syphilis. At the time, the natural course of the disease was poorly understood, so the researchers wanted to observe the men without treatment to see what happened. They promised the men medical care if they cooperated – when in fact the whole point of the research was not to treat their syphilis."

[10] *See* John F. Harris & Michael A. Fletcher, Six Decades Later, an Apology; Saying 'I am Sorry,' President Calls Tuskegee Experiment 'Shameful,' Wash. Post, May 17, 1997, at A01.

[11] Daniel Q. Haney, Out Front: Journal Questions Ethics of Study to Stop Infant AIDS, Associated Press, Sept. 17, 1997, *available in* 1997 WL 4883943 (quoting Dr. Catherine Wilfert, medical director of the Pediatric AIDS Foundation).

director of the National Center for HIV, STD, and TB Prevention at the CDC, Helene Gayle, quickly responded that, unlike the Tuskegee participants, the women in the HIV studies are fully informed of the risks and benefits.[12] Moreover, she argued, the women in these tests would not have access to any effective treatment for HIV if they were not enrolled in the studies.[13]

The application of the doctrine of informed consent in these experiments raises several complicated issues concerning its ability to realize the Nuremberg Code's core tenets of protection of and respect for the individual. Is consent, premised on a volunteer's free will to choose, necessarily evident simply because the tests are not conducted under the flagrant abuses of the fascist Nazi regime? This article seeks to demonstrate the problematic nature of structuring a test regimen on the condition of the freely obtained consent of individuals who are not similarly situated to the researchers in terms of power or resources. Offering a chance of free health care to indigent, pregnant HIV-positive women compels a reanalysis of how the often illusory qualities of consent are manifested in medical experimentation on relatively unempowered subjects. Thus, Part I of this article will begin by offering a brief history of the modern doctrine of informed consent and describe its application in these HIV experiments. It will then examine the manipulation of the doctrine of informed consent as the crucial element which allows researchers to hail the experiments as ethically sound, while simultaneously perpetuating the myth that the women involved were in a position to choose of their own free will to participate.

Part II will address a key issue raised by these experiments: the hotly contested use of the cultural relativism defense when studies are conducted on "foreign" bodies.[14] The essential question is whether standards of care in America should frame standards of care in countries too poor to afford the "luxury" of test regimens that were designed to protect the autonomy of the individual and guard against treating individual subjects as means to a greater social good. (Moreover, it is also worth asking whether this standard really even exists in America.) The relativist debate compels an analysis of the normative features of the Nuremberg Code and its successors to

---

[12] *See* Susan Okie, Researchers Assailed for AIDS Studies on Pregnant Women in Third World, Wash. Post, Sept. 18, 1997, at A13.

[13] *See id.*

[14] Cultural relativism is the "anthropological perspective that withholds any condemnation of 'cultural practices' of communities not one's own." Leti Volpp, (Mis)Identifying Culture: Asian Women and the "Cultural Defense", 17 Harv. Women's L.J. 57, 83 (1994).

determine whether they are essentially Western in nature, and thus not always applicable in a multicultural context. Upon close inspection, however, the relativist defense is undermined by its advocates' misplaced conflation of culture with politics and economics. Thus, this Part examines the role of politics in the context of these HIV tests to demonstrate how standards of care and research are not so much the product of one's culture, but rather the effect of a global market system that effectively excludes access to life-saving drugs to a large portion of the world that desperately needs them—the overwhelming majority of whom are poor persons of color. It concludes that relativism can be a valid critique of Western attitudes toward other cultures; however, in this context, a more sophisticated approach that scrutinizes how to identify culture and adheres to the principles of "intersectionality" and "antisubordination" is better suited to promoting the goals of the Nuremberg Code.

Part III addresses why the fallibility of the doctrine of informed consent mandates an analysis of other methods of fulfilling the Nuremberg Code's mission. Recent analyses exploring how property law determines and perpetuates power and control over others provide instructive models of how to protect the test subjects' bodies by providing these women with the resources necessary to make the decision to "volunteer" in the spirit of choice and autonomy inherent in informed consent. Maintaining a focus on the process of distribution of goods and the connection of property to personhood, this Part contends that a property theory of one's bodily integrity can provide a better vehicle than the concept of consent for achieving the promises of the Nuremberg Code and honoring the memory of the victims for whom it was created.

I. THE MYTH OF INFORMED CONSENT

One of the primary differences between the Tuskegee experiment and the current HIV tests lies in the application of the doctrine of informed consent. This principle, aimed at protecting human subjects involved in medical research experiments, posits that each participant should receive a comprehensive explanation of the test's risks and benefits and, based on this information, choose to participate of his or her own free will. Because informed consent is considered such an important requirement in any medical experiment involving humans, its application in the HIV experiments must be interrogated for its inability to protect the bodies and health of participants not capable of choice in the spirit of the doctrine. After a brief summary of the history of the doctrine of informed consent in medical experiments, this

Part will demonstrate how the doctrine's essential purpose to protect individuals has failed in the context of these HIV experiments.

The modern doctrine of informed consent for human experimentation grew largely out of the Nuremberg Code of 1949.[15] In response to Nazi Germany's coerced science and medical experiments on human subjects, the Code's first principle unequivocally declared that

> the voluntary consent of the human subject is essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision.[16]

The Code's language undeniably reflects a desire to guard against the type of atrocities that induced its conception; references to "voluntary" consent and "free power of choice" clearly envision the doctrine's application in a context involving autonomous, empowered individuals.

The Nuremberg Code's emphasis on the notion of informed consent has been affirmed by several successive declarations and codes concerning human experimentation. In 1964, the Declaration of Helsinki also adopted the informed consent provision.[17] Together, these two documents are considered the primary source of ethical guidelines for medical research on humans.[18] Strengthening the informed consent provision in later declarations, in 1989 the Declaration of Helsinki of the World Health Organization issued ethical guidelines concerning informed consent which are now "widely regarded as providing the fundamental guiding principles of research

---

[15] *See* Kathryn A. Tuthill, Human Experimentation: Protecting Patient Autonomy Through Informed Consent, 18 J. Legal Med. 221, 247 (1997). The Code was formulated by United States Judges who presided over the trials of Nazi physician/experimenters following World War II. *See* George J. Annas, The Changing Landscape of Human Experimentation Nuremberg, Helsinki, and Beyond, 2 Health Matrix 119, 120 (1992).

[16] 2 Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10, 181-82 (1946-1949).

[17] *See* Annas, *supra* note 15, at 122.

[18] *See* Evelyn Shuster, The Nuremberg Code: Hippocratic ethics and human rights, The Lancet, March 28, 1998, at 1.

involving human subjects."[19] One of these principles mandates that "[t]he ethical standards applied [abroad] should be no less exacting than they would be in the case of research carried out in [the sponsoring] country." It also states, "In research on man [sic], the interest of science and society should never take precedence over considerations related to the well-being of the subject." Moreover, "In any medical study, every patient—including those of a control group, if any—should be assured of the best proven diagnosis and therapeutic method."[20] These tenets embody two of the Declaration's critical concerns: first, that the individual human subject's health is valued over competing gains to others, and second, that the best known treatment available be used. To ensure that these principles are honored, the Nuremberg Code and the Declaration of Helsinki both incorporate the doctrine of informed consent.[21]

Experiments in developing nations, however, offer complicated challenges to the efficacy of informed consent. A recent breast cancer experiment in Britain, which also used placebos, revealed some significant differences between the application of informed consent in an industrialized, wealthy nation and its use in a developing one. The British study, which aimed to recruit enough volunteers to conduct a scientifically valid study of a new drug to prevent breast cancer in women whose family history indicates that they are at a high risk of the disease, had difficulties reaching its quota. Commenting on the reluctance of many potential volunteers, a journalist framed the dilemma by asking: "[W]hat scientifically aware adult is really going to agree to a course of 'medication' which might be a useless sugared pill, letting their illness go untreated?"[22] This rhetorical question was later addressed by one of the British researchers in an apt assessment of the relative differences in subject attitudes: "The trouble is, taking part means accepting the risk that actually, you're just standing on the sidelines—and that's something which people in the modern world seem unwilling to accept."[23] Implicit in the doctor's analysis is the obvious fact that people in

---

[19] Angell, *supra* note 9, at 847.

[20] *Id.*

[21] *See* Carel B. IJsselmuiden & Ruth R. Faden, Research and Informed Consent in Africa—Another Look, 326 N. Engl. J. Med. 830 (1992).

[22] Charles Arthur, Science: Are Scientific Trials Blind to Suffering, The Independent (London), Oct. 28, 1997, at N8.

[23] *Id.*

the "modern" world, those with financial resources, don't *have* to accept standing on the sideline; they have the resources to make a choice.

The above example illustrates the differences when relying on informed consent in a wealthier, industrial nation, as opposed to a developing one, to provide the necessary "freedom" to participants to volunteer, and thus qualify an experiment as officially ethical. In contrast to the British study, conducting experiments on "volunteers" in poorer countries often raises the dilemma that relatively low educational levels, offers of payment, or the provision of otherwise unavailable medical services may induce residents of these developing countries to take risks that persons in developed countries would find unacceptable.[24] This inequality of knowledge, authority, and wealth between the researcher and volunteer is a prime reason why Marcia Angell, editor of the *New England Journal of Medicine*, and one of the leading critics of the HIV tests, alleged that informed consent cannot adequately protect these women.[25] Yet, as a testament to the necessity of a formalized informed consent procedure, it was considered a crucial factor in the *New England Journal of Medicine*'s ultimate decision to find the experiments officially "ethical" and therefore approved for publication.[26]

Testimony from some of the African participants in these studies offers compelling reasons to doubt the sufficiency of informed consent, regardless of the researchers' good intentions; indeed, many participants have expressed confusion about the test. One twenty-three-year-old infected mother was questioned repeatedly by a journalist about what a placebo is and why it was being used. She responded, "They gave me a bunch of pills to take and told me how to take them. Some were for malaria, some were for fevers, and some were supposed to be for the virus. I knew that there were different kinds, but I figured that if one of them didn't work against AIDS, then one of the other ones would."[27] Like many of the participants, this mother was illiterate, unemployed, and unmarried. A reporter for the *New York Times*, Howard French, noted that this mother's reasons for enrolling in

---

[24] See Ileana Dominguez-Urban, Harmonization in the Regulation of Pharmaceutical Research and Human Rights: The Need to Think Globally, 30 Cornell Int'l L.J. 245, 271 (1997).

[25] *See* Angell, *supra* note 9, at 847.

[26] *Id.* at 848. The *New England Journal of Medicine* has a policy that it will not publish reports of unethical research, regardless of their scientific merit. The majority of editors voted to approve this research for publication.

[27] Howard W. French, AIDS Research in Africa: Juggling Risks and Hopes, NY Times, Oct. 9, 1997, at 1A.

these tests were clear to her: "It offered her and her infant free health care and a hope to shield her baby from a deadly infection."[28]

French conducted extended interviews with some of the women involved in the research, and found that many of the participants did not grasp the ethical and scientific issues involved.[29] Observing an actual briefing by social workers and nurses about the nature of the testing program, he describes the cursory manner in which the details of the test are presented:

> Minutes after [the participant] was informed for the first time that she carried the virus, [the] pregnant woman, Siata Ouattara, still visibly shaken by the news, was quickly walked through the details of the tests. . . . In less than five minutes, in which the previously unknown concept of a placebo was briefly mentioned, the session was over, and Ms. Ouattara, unemployed and illiterate, had agreed to take part in the tests. Asked what had persuaded her to do so, she responded, 'the medical care that they are promising me.'[30]

Her experience echoes that of another participant, a twenty-eight-year-old seamstress, who told reporters, "I don't remember exactly what they told me. . . . They said that it would help my child, and that it would ease my childbirth too."[31]

An interview with one of the most highly educated participants, a single mother who had a degree in law, illustrates that full disclosure and comprehension were not the only impediments; the subjects' lack of

---

[28] *Id.*

[29] *Id.* While the comparisons to the Tuskegee experiment can be considered an inflammatory tactic by critics, these comments by the HIV participants eerily echo comments by some of the Tuskegee survivors. A historian of the Tuskegee incident interviewed some of the survivors after the governmental deception had been exposed, and found that while some expressed anger over the experiments, others remained confused. He writes that some "had great difficulty making sense of the study. After commenting that he and his friends had been used as 'guinea pigs,' another survivor confessed: 'I don't know what that means. . . . I don't know what they used us for.' The same man added: 'I ain't never understood the study.'" James H. Jones, Bad Blood: The Tuskegee Syphilis Experiment 219 (1993).

[30] French, *supra* note 27, at 1A.

[31] *Id.*

resources and access to this medication also bore heavily on the "decision" to volunteer. Giving her name only as Nicole, the woman explained that the researchers never explained to her that AZT, the medicine being tested, had been discovered prior to these tests to block transmission of the virus during pregnancy: "I am not sure that I understood all of this so well. But there were some medicines that they said might protect the mother and the child, and they wanted to follow the evolution of my pregnancy and the effectiveness of the treatment." When asked "how she would feel if she learned tomorrow that she had received a placebo when a proven treatment existed," the reporter notes that "Nicole's tone changed abruptly. 'I would say quite simply that that is an injustice.' Regathering her composure, Nicole posed the problem another way. 'At the time they explained this to me, I asked myself the simple question of whether I had any choice. As long as there was a possibility to save my daughter, I had to try.'" This sentiment was echoed by other mothers, who, French reports, "acknowledged that they understood little" of the tests but hoped to save their children or get "free health care" that they could not otherwise afford.[32] These statements stand in sharp contrast to the CDC's repeated assertion that "[w]omen are clearly told that the AZT regimen might or might not be effective. . . . It is clearly explained to the women involved that some would receive AZT and others would receive a placebo."[33]

The participants' words provide the most compelling evidence that both prongs of the informed consent doctrine, (1) to be sufficiently informed, and (2) to consent freely, have not been met. Apart from the dubious procedure of obtaining informed consent just minutes after informing a pregnant woman that she is HIV-positive, these reports challenge the more substantive idea that consent can ever be an option.[34] Free will is largely an illusion in these experiments when it is contingent on the subjects being "so situated" as having the power to choose, and power in this context means having access to health care and life-saving medication. The observation of a coordinator of the Ivory Coast study reinforces the idea that the power to

---

[32] *Id.*

[33] Charles W. Henderson, CDC Explains Its Stand on Controversial Third World AZT Study, AIDS Weekly Plus, July 28, 1997, *available in* 1997 WL 11006847.

[34] *See* George J. Annas, Standard Care: The Law of American Bioethics 135 (1993). Illustrating the reality of consent for participants who are already sick, Annas writes that "[i]ncapacitated and hospitalized because of illness, frightened by strange and impersonal routines, and fearful for his health and perhaps his life, he is far from exercising a free power of choice." (quoting F. Ingelfinger, Informed (But Uneducated) Consent, 287 New Eng. J. Med. 465-66 (1972)).

choose for these volunteers is especially problematic: the female participants are "almost entirely economically dependent on men and [in] fear [of] stigmatisation and abandonment."[35] Indeed, recent studies and reports have focused on the economic and social forces that simultaneously operate to subordinate women and facilitate the spread of HIV. Some of these factors include an illiteracy rate almost fifty percent higher among women than men, legal prohibitions against ownership of property by women in several African nations, and a pervasive attitude that women must yield sexual decision-making to men.[36] Thus, given the myriad of economic and social factors that operate to oppress these female participants, and their lack of alternatives, it is deeply problematic to label their decision to volunteer a freely made choice.

Beyond the dubious application of informed consent in these experiments, historical examples of unethical experimentation on human subjects in the United States as well as abroad demonstrate a disproportionate number of poor and unempowered "volunteers." While the notorious Tuskegee syphilis experiment failed to obtain any informed consent at all, other incidents illustrate the ability of researchers to procure "informed consent" through manipulation and coercion.

For example, ten years ago Tampa General Hospital conducted amniocentesis research on indigent women while ostensibly obtaining informed consent. One participant, a sixteen-year old, was "drugged and barely coherent" when the consent form was thrust upon her. The girl's mother, who had great difficulty reading English, was told by the physicians that if they were not permitted to proceed, her daughter's baby would die.[37]

Another incident that involves American pregnant women of color and coercive consent can be seen explicitly in the HIV context. In urban settings, many providers of prenatal care to low-income women are reimbursed more generously for counseling sessions that result in a woman's decision to consent to HIV testing. Consequently, the pressure to obtain consent has swayed "even the most ethical counselors."[38] One former HIV

---

[35] Jane Feinmann, Tackling Mother-to-Child HIV in Cte d' Ivoire, The Lancet, Oct. 11, 1997, *available in* 1997 WL 14874854.

[36] *See* Mark Schoofs, AIDS: The Agony of Africa—Part 5: Death and the Second Sex, The Village Voice, Dec. 1, 1999, at 40.

[37] *See* Tuthill, *supra* note 15, at 246.

[38] Suzanne Sangree, Control of Childbearing by HIV-Positive Women: Some Responses to Emerging Legal Policies, 41 Buff. L. Rev. 309, 342 (1993).

counselor stated that "to call what they did 'counseling' is a complete misrepresentation. Informed consent counseling is meant to facilitate a patient's free will. They had the explicit agenda to obtain consent for testing."[39]

Other examples outside the medical research field also demonstrate how the concept has been exploited and manipulated at the expense of marginalized social groups. In Louisiana and Kansas, male legislators have proposed the use of Norplant by its poorer citizens to reduce the need for state aid. One Kansas representative introduced a bill in 1991 that "if approved, would pay welfare mothers $500 if they would *consent* to getting the Norplant contraceptive."[40] In a similar episode, a California Superior Court Judge ordered a twenty-seven-year-old woman to "consent to be implanted with the birth control Norplant" as a condition of her probation for a drug conviction.[41] As one author explains, judicial sanctions and legislation aimed at curtailing reproductive freedom of drug-using women will have a disparate impact on women of minority communities: "[P]ublic hospitals, where poor women go for care, are most vigilant in their drug testing and more likely than private hospitals to report women whose tests show drug use."[42] Even more troubling is the judiciary's willingness to force the defendant's consent, draining the concept of any notion of choice.

These examples demonstrate why consent is extremely problematic, especially when it involves great inequities in power between the test subjects and those responsible for obtaining their consent. Attempts in America to coerce the consent of the poor and persons of color suggest that the ethics of the doctrine of informed consent, as advanced in the Nuremberg Code and Declaration of Helsinki, are largely contingent on the situation of the subject. As long as the participants in an experiment are marginal actors in society, informed consent will continue to perpetuate the fiction of one's choice to participate. The HIV experiments abroad and the examples in America

---

[39] *Id.*

[40] Barbara L. Bernier, Class, Race, and Poverty: Medical Technologies and Sociopolitical Choices, 11 Harv. Blackletter L.J. 115, 135 (1994) (emphasis added). The bill eventually died in committee. *See also* Martha A. Fineman, The Neutered Mother, The Sexual Family and Other Twentieth Century Tragedies 190 (1995). Describing this proposal, Fineman writes, "One must wonder about the use of the term 'voluntary' in the context of an AFDC [Aid to Families with Dependent Children] recipient, who is already living on a stipend below the poverty level. When confronted with an economic 'incentive,' the notion she has a choice in such circumstances seems illusory."

[41] Bernier, *supra* note 40, at 137.

[42] *Id.*

demonstrate an overly permissive attitude by many researchers, legislators, and other officials to exploit the concept of consent to further their own notion of social welfare.[43]

The application of the doctrine of informed consent in American experiments on subordinated and marginalized persons implicates many of the same problems as the HIV experiments abroad. However, when HIV tests are performed in non-Western cultures, advocates of the research design have put forth a conspicuous counterargument. Recognizing that informed consent, as envisioned by the Nuremberg Code, is dubious in these experiments, the CDC offers an equally dubious rationale for the test regimen: that opponents of the tests are engaging in "ethical imperialism" and that research in non-Western cultures should not be dictated by Westernized views of the individual and her capacity to give informed consent.

II. RELATIVISM AND INFORMED CONSENT

Challenging the allegations of unethical behavior, the CDC and other supporters of the tests argue that these critics are engaging in "ethical imperialism" by attempting to "export" the Westernized doctrine of informed consent to developing countries[44]—which may have a communitarian outlook and lack the Western concept of an autonomous "self" or "personhood"—and by imposing American standards of care on nations which cannot afford them.[45] These justifications are espoused by leading doctors and bioethicists; for example, the esteemed AIDS researcher Dr. David Ho declares, "While

---

[43] Numerous examples of this abuse in international settings have been noted by the ethical watchdog group Public Citizen. For example, in China, live malaria parasites were injected into HIV-Positive subjects in order to study the effect of the progression of the HIV infection. This study protocol had been rejected in the United States. In another example, malnourished San (bushmen) were randomly assigned to receive vitamin-fortified or standard bread. Experiments such as these have prompted the Public Citizen's Health Research Group to urge that "[r]esidents of impoverished, postcolonial countries, the majority of whom are people of color, must be protected from potential exploitation in research. Otherwise, the abominable state of health care in these countries can be used to justify studies that could never pass ethical muster in the sponsoring country." *See* Lurie & Wolfe, *supra* note 2, at 855.

[44] Dominguez-Urban, *supra* note 24, at 280.

[45] *See* Joseph Saba and Arthur Amann, Drug Tests Offer Hope to Victims, The Arizona Republic, Sept. 23, 1997, at B7. Dr. Joseph Saba works for the Joint United Nations Program on HIV/AIDS (UNAIDS).

the inclusion of this placebo group would not be acceptable in the United States, the sad truth is that giving nothing is the current standard of care in Africa."[46] Another doctor bluntly asserts, "[t]he facts are different in different places."[47] Affirming this position, some doctors and researchers originating from the host countries have argued, "Americans should not impose their standards of care on developing countries,"[48] and "[l]ocal health experts, bioethicists and affected groups are best qualified to judge the risks and benefits of any medical research."[49] Thus, by focusing on the Western origins of the informed consent doctrine, the sponsors of these tests invoke a relativist argument that would preclude imposing burdensome American values and requirements on other nations.

This Part will explore the foundation of the relativist argument, and argue that relativism is an inappropriate defense in this context because it wrongly focuses on "culture" rather than the politics and economics of the health care/drug market as the principle factors driving these research decisions. It concludes that while relativism can be a valid critique of Western attitudes toward other cultures, a more nuanced approach that scrutinizes how to identify culture by applying the principles of "intersectionality" and "antisubordination" is necessary to distinguish when relativism is a valid defense.

As the doctrine of informed consent has become an international standard governing experiments involving humans, greater attention has been focused on its application in multicultural contexts. One critic of the Westernized doctrine's application to non-Western cultures notes, "[t]he law on informed consent represents a struggle to find patients' voice [sic] in medical decisionmaking and to level the playing field between patients and their physicians. The voice discovered, however, echoes a notion of autonomy based on Western cultural values."[50] This analysis identifies two

---

[46] Dr. David D. Ho, It's AIDS, Not Tuskegee; Inflammatory Comparisons Won't Save Lives in Africa, Time, Sept. 29, 1997, at 83.

[47] Sheryl Gay Stolberg, American Aids Study Overseas Now a Test of Ethics, The Plain Dealer, Sept. 18, 1997, at 14A (quoting Dr. Norman Fost, director of the medical ethics program at the University of Wisconsin).

[48] Saba & Amann, *supra* note 45, at B7.

[49] *Id.*

[50] Elysa Gordon, Note, Multiculturalism in Medical Decisionmaking: The Notion of Informed Waiver, 23 Fordham Urb. L.J. 1321, 1328 (1996). *See also* Michele Barry, Ethical Considerations of Human Investigation in Developing Countries: The AIDS Dilemma, 319 N. Engl. J. Med. 1083 (1988) (explaining that "[w]hereas in Western terms selfhood emphasizes the individual, in certain African societies it cannot be extricated from

aspects of the doctrine that reflect the Western tradition: "First, informed consent emphasizes the right of the individual to make decisions concerning medical treatment. . . . [Second], it envisions the active participation of the individual patient in medical treatment and decisions about treatment." The argument concludes that by "insisting on a singular notion of autonomy, defined by Western values and applied to all individuals, [Western beliefs] fail[] to respect individual autonomy in a different and fuller sense by diminishing an individual's right to decide how and by whom decisions of consequence to his or her life are made."[51] This argument was echoed by Hoosen Coovadia, the head of the pediatrics and child health department at the University of Natal in South Africa and chairman of the International Conference on AIDS in 2000, who noted that "[w]hat works in the United States, which values individual rights, may not work in developing countries where community needs supersede individual ones."[52]

The WHO/CIOMS (Council of International Organizations of Medical Science) Guidelines of 1982 addressed this concern by providing a more "flexible approach" to the doctrine of informed consent.[53] The Guidelines assert that "freely-elicited informed consent" should be obtained "whenever feasible" but recognize that this "goal may be unobtainable." Focusing on the dilemma of securing informed consent in a "communally-oriented society," the Guidelines provide for "consent through a trusted intermediary or community leader. . . ."[54] This approach, not followed in the Declaration of Helsinki, has been cited by researchers as persuasive authority that condones a relative approach to ethical considerations contingent on some form of community support or approval.[55]

---

a dynamic system of social relationships, both of kinship and of community as defined by the village").

[51] Gordon, *supra* note 50, at 1328.

[52] A Growing Dichotomy: The Gap Between Therapeutic Haves and Have-Nots, Aids Alert, Jan. 1, 1998, *available in* 1998 WL 9747452.

[53] Dominguez-Urban, *supra* note 24, at 274.

[54] World Health Org. & Council for Int'l Org. of Med. Science, Proposed International Guidelines for Biomedical Research Involving Human Subjects, *reprinted in* Human Experimentation and Medical Ethics 387 (Zbigniew Bankowski & Norman Howard-Jones eds., 1982).

[55] *See* Angell, *supra* note 9, at 848; Henderson, *supra* note 33, at 1.

The experiments in Uganda provide a useful illustration of the difficult questions raised by the 1981 WHO/CIOMS approach to applying the doctrine in non-Western, and usually developing, nations. In 1994, James Makumbe, Minister of Health for Uganda, announced that Uganda was "ready to provide subjects for HIV vaccine trials in return for health care services."[56] Apparently, the Minister of Health decided that Ugandan citizens were prepared to submit to trials developed by Western health organizations. The exchange for services, however, suggests that politicians in Uganda have bartered with the lives and persons of its HIV population in exchange for desperately needed health care. While the Minister undoubtedly promoted this pragmatic, utilitarian approach to help curb the epidemic in his country, the proposal does leave the impression that HIV-positive citizens are expected to comply with tests designed by nations such as the United States. And, considering the statements by the pregnant participants, most people would enlist just for a shot at free health care. In a testament to Uganda's reliant position in the structure of these tests, Minister Makumbe acknowledged that "[t]he need for a placebo is difficult to explain, but acceptable if the placebo has some benefit."[57]

The Minister's words are echoed by Ugandan scientists assisting in tests formulated by WHO and the CDC. Responding to allegations of unethical behavior, they state,

> The ethical issues in our studies are complicated, but they have been given careful thought by the local community, ethicists, physicians and activists. Those who can speak with credibility for AIDS patients in Africa are those who live among and know the people here or have some basic cross-cultural sensitivity. We are suspicious of those who claim to speak for our people, yet have never worked with them.[58]

The concession that ethics are "complicated" in these studies is most likely a reference to the fact that the lack of health care resources in Uganda means that none of these women would have a chance of obtaining AZT

---

[56] Charles Henderson, Uganda Will Provide Vaccine Subjects in Return for Services, Infectious Disease Weekly, Mar. 4, 1996, at 1.

[57] *Id.*

[58] Bagenda & Musoke-Mudido, *supra* note 6, at C03. Danstan Bagenda is a biostatistician at Makerere University Medical School in Kapala. Philippa Musoke-Mudido is a pediatrician at Makerere.

were it not for these tests.[59] In other words, the tests are better than nothing and this country cannot afford the luxury of rejecting studies not in conformance with standards required in America. Taken together, the statements of the Minister of Health and the local doctors conducting the tests acknowledge a communal-oriented approach regarding the ethical appropriateness of these tests, at least to the degree that communitarianism represents a utilitarian perspective.[60]

The paradox of this position is that the scientists, while decrying American criticism of the programs for their inability to "know" what is appropriate for Uganda, were essentially dictated to by American agencies that mandated the placebo method. Since these nations are not going to be given AZT at a heavily subsidized rate, those in charge had very little choice but to accept whatever test regimen was developed by the United States. Thus, these experiments cannot be viewed as a product of Ugandan culture or somehow unknowable by Western critics because they are genuinely Western in nature. The reason these scientists challenge the tenet of the Nuremberg Code and Declaration of Helsinki that prohibits placing the greater good ahead of the individual subject is not because it is Western, but rather because it privileges societies rich enough to afford choice and autonomy. In this sense, the doctrine does not embody Western values, but presumes privileged status. The relativist claim here, then, is misguided because it conflates culture with economics and pragmatics.

---

[59] The CDC has asserted this reason as a justification for its research regimen: "[o]ne of the most important ethical considerations in conducting clinical trial research is that participants in the research should not receive less care than would be available to them if they were not involved in the research." Henderson, *supra* note 33.

[60] An interesting parallel to these tests can be seen in the "consent" of Native American tribes to store nuclear waste on their land in exchange for monetary compensation. In the case of the Mescalero Apache Indians of New Mexico, tribal leaders voted to approve the waste site in the face of serious objections by many tribe members. Because the economic conditions of the reservations are so dire, many Native American lands are aggressively sought after by private companies seeking to store toxic waste. Lance Hughes, the Executive Director of the Oklahoma-based Native Americans for a Clean Environment, has argued that, "the Bureau of Indian Affairs has failed miserably in its mandate to foster economic development on reservations. As a result, tribes are more apt to entertain questionable proposals from waste companies. *See* Noah Sachs, The Mescalero Apache Indians and Monitored Retrievable Storage of Spent Nuclear Fuel: A Study in Environmental Ethics, 36 Nat. Resources J. 641, 659 (1996). The tribal leader's willingness to consent to a potentially dangerous situation for its members demonstrates another example where an individual's consent has been given by someone identified by others as authorized to give this consent.

A comparison to the controversy over female circumcision, another human rights issue that implicates the cultural relativism debate, demonstrates how the dominant role of the American health organizations in the HIV experiments distinguishes them from a relativist debate on other cultural practices. Karen Engle, discussing the practice of female circumcision, identifies several approaches Western human rights groups have adopted to stop this ritual; her aim is to explore how these methods confront or circumvent culturally relativist arguments. Because female circumcision is largely performed by women, and also supported by some women, the relativist counter-claim poses a challenge for Western feminists. The approach she labels "doctrinalist" is the most pertinent in this context because its followers confront the relativist claim, but summarily dispose of it by championing a universal human rights doctrine.[61] Rather than dismissing these women, the "Exotic Other Female," as having false consciousness, the doctrinalists engage in a "strategic positivism" which aims to stress whichever rights will be the most persuasive in convincing these women that the practice is oppressive.[62] A similar approach has been advocated by one medical ethicist regarding research on human subjects:

> One approach to this issue is to hold that privacy is a derivative moral concept, not a fundamental one. It derives from a philosophy of individualism, as does the 'respect for persons' principle discussed . . . in connection with informed consent. But the principle demanding respect for persons is fundamental. The wrongness of acts or practices such as enslavement, exploitation, torture, and degradation is a moral judgment not culturally limited to the perspective of Western individualism. These acts are violations of a moral prohibition that ought to be universally acknowledged.[63]

---

[61] *See* Karen Engle, Female Subjects of Public International Law: Human Rights and the Exotic Other Female, *in* after identity: A Reader in Law and Culture 212 (Dan Danielsen & Karen Engle, eds. 1995). The two other approaches Engle describes are called "institutionalist" and "the external critique."

[62] *Id.* at 214. Engle explains that she uses the term "Exotic Other Female" as "a signifier, to represent collectively those women who through their action (or inaction) condone the practice of clitoridectomy within their culture. Implicit in this label is the assumption that the Exotic Other Female, or at least her needs and desires, are not totally accessible to someone outside her culture." *Id.* at 212.

[63] Ruth Macklin, Universality of the Nuremberg Code, *in* The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation 248-9 (George J. Annas and Michael A. Grodin, eds., 1992) [hereinafter Nazi Doctors].

At first glance, this argument would appear to offer a workable conception of ethics premised on the notion that "fundamentally" we are all the same, and thus deserving of respect for our autonomy which would preclude exploitation—even if it were ultimately to benefit others. But, this approach, like the doctrinal approach, fails to account for the existence of genuine cultural differences among individuals from different cultures that often transcend Western views of "exploitation" and other moral judgments.

The vital difference, then, in the debate over the appropriateness of a relativist defense of female circumcision and the HIV tests is the identification of culture. As Engle demonstrates, clitoridectomy has been practiced for centuries by women, primarily located in Muslim Africa, and is often desired by at least some of the girls. Engle astutely exposes the problems inherent in a critique on this "tradition" that stem from an inability of Western feminists to recognize and respond to differences among women; they imaginatively construct the "Exotic Other Female" as someone either to dismiss or inform, yet refuse to engage her directly. In the HIV tests, however, no cultural tradition has been advanced to counter claims of unethical Western research. Standards of health care, defined in this context as access to life-saving drugs, are *not* cultural norms, but are products of a market that perpetuates inequities and the effects of colonialism. By invoking a relativist claim in this context, supporters of the tests risk conflating cultural tradition with pragmatic principles dictated by harsh economic realities. Thus, by exposing the inappropriateness of the relativist defense in this context, the willingness of American agencies to manipulate the spirit of the doctrine of informed consent in relation to less empowered and marginalized subjects can be more readily examined.

While relativism is an inappropriate counterargument to objections against the HIV tests because it justifies the economic subjugation of these populations as "culturally" relevant to ethical standards and guidelines, the notion that cross-cultural sensitivity applies in an informed consent analysis remains a significant issue: by what process should a researcher identify and incorporate legitimate cultural differences, without perpetuating cultural stereotypes often sustained by post-colonial economic conditions and inter-cultural oppression. Thus, while the doctrinal approach has some merit, its tendency to "equalize" everybody without conducting a more probing analysis into the situated differences of individuals is problematic. As Engle demonstrated, what constitutes exploitation or degradation must be informed by one's cultural experience. Consequently, these concepts pose the daunting challenge of finding a consensus definition among a myriad of cultural experiences. Thus, considering the fact that experiments such as these overwhelmingly involve the poor and people of color, an approach to this

problem is needed that will accommodate the realities of cultural differences while carefully scrutinizing what truly is "cultural." In other words, attention to cultural differences is still a relevant and necessary consideration in the examination of non-Western practices—indeed, a charge of ethical imperialism could exist in certain test regimens—but not when economic realities dictate and coerce the testing regimen and compel voluntary participation. The examples of questionable procedures used in America to obtain informed consent from poor and marginalized subjects cited in Part One demonstrate that a doctrinal/fundamental perspective is limited because it is largely inapplicable in situations where ethical imperialism is possible; thus, a more nuanced approach that utilizes an "intersectional" analysis of the social, economic, and cultural forces that subordinate certain individuals is better suited to address the key issue in these experiments (both here and abroad)—protecting the unempowered.

Support for an intersectional analysis of the cultural relativism dilemma can be found in the arguments comprising the debate on cultural defenses in the American judicial system. One of the challenges cultural defenses pose for the American judicial system is how to reconcile the desire to respect a defendant's specific cultural experience—which can explain specific motivation/action as reasonable or serve to mitigate punishment—with the need to penalize behavior considered morally wrong in this culture. Because many similarities exist between these two dialogues, the scholarship advanced on the appropriateness of cultural defense with regard to relativism and the need to respect the integrity of all individuals can assist in an analysis of the abuses of the informed consent doctrine.

A key issue in the debate on cultural defenses centers on the relationship of culture to subordination. In a recent article, Leti Volpp advocates the value of using an intersectional analysis when deciding when and how cultural factors should be admissible as a defense.[64] Her aim is to interrogate the categorization of the individual defendant to determine when inclusion of the cultural defense will not assist in understanding a particular defendant's situation, but rather serve to perpetuate stereotypes and subjugation. In other words, Volpp exposes how complex power dynamics and multiple oppressions facilitate the construction and perception of identity and "culture," and sustain the subordination of certain individuals. By employing an intersectional analysis, she seeks to promote the principle of antisubordination—defined as the "serious commitment to evaluating and

---

[64] *See id.*, at 59. For an excellent analysis of intersectionality and its application, *see* Kimberle Crenshaw, Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color, 43 Stan. L. Rev. 1241 (1991).

eradicating all forms of oppression."[65] This focus on antisubordination and intersectionality offers an informative perspective on the nature and effects of the HIV experiments. As opposed to the doctrinalist approach, Volpp's theory encourages greater attention and thought to the inequities in power and choice characteristic of these experiments. Rather than starting from the premise that all individuals are essentially the same, and thus deserve a universal baseline of respect and rights, Volpp chooses to incorporate this universal entitlement into a framework more reflective of how traditional hierarchies have encouraged and sustained these inequities. She does this to balance the difficult task of deciding when use of culture is appropriate and when it is not (and, implicitly, what is and what is not "culture").

Applying the principle of antisubordination to the cultural defense dilemma, Volpp uses the example of domestic violence among Asian-American couples to illustrate how culture can be misidentified:

> My concern is that domestic violence among Asian-American communities is explained as "cultural," when a similar description is rarely given to domestic violence in the heterosexual white community. This masks the severity of violence against Asian women by describing it as a "practice" rather than as a political problem. Moreover, to explain behavior as "cultural" implies that it is insular to Asian communities and that the dominant society bears no relationship to that behavior.[66]

Thus, a Chinese man killing his wife because he feels "dishonored" by her perceived infidelity, to use one of her examples, would not be an act privileged as "culture" for the benefit of a defense. To permit a cultural defense in this situation to explain the individual defendant's state of mind is to reify cultural stereotypes and misidentify "culture." In contrast, Volpp describes a case where a Chinese mother, after suffering severe abuse by her husband, kills her son and then attempts suicide— in an act intended to deliver them both to heaven—to explain how the antisubordination approach would operate to allow a cultural defense in this case while barring it in the

---

[65] *See* Volpp, *supra* note 14, at 98.

[66] *Id.* at 94. Volpp further explains this concern by giving the following example: "[I]mmigrant women's difficulty in gaining access to the battered spouse waiver to the Marriage Fraud Amendments is not perceived as linked to the lack of translated materials or to the absence of laws that promote the interests of poor immigrant women. Rather, that lack of access is often explained as caused by a woman's 'culture.'" *Id.* at n.161.

former scenario: "Antisubordination, as premised on the vastness of oppression along unidirectional lines, such as male oppression of women, and xenophobic oppression of immigrants, must be the value on which we base our choices of whether to support the use of cultural factors in a defense and what information should be presented."[67] This is not, Volpp stresses, to say that antisubordination privileges "who's most oppressed," but rather that this approach strives to end the perpetuation of stereotypes while highlighting the position of the individual in the hierarchy of power.[68] Thus, greater attention would be given to the woman's position as the victim of male oppression to explain her "criminal" behavior.

Volpp's discussion of how the label "culture" can operate to mask the causes for and contributions to a particular "practice" offers a valid insight into the defense of cultural relativism in the HIV experiments. Her emphasis on the multiple expressions of power in determining how individuals are situated to one another, and how this power is perceived by those both within and without a specific identity group, facilitates the most effective method of understanding the essential dynamic in the application of the informed consent doctrine. In other words, this antisubordination approach provides a valuable guide in determining when cultural differences are a valid factor in the determination of a test regimen as "ethical." By identifying the inadequacy of health resources as a political problem—one to which the dominant Western culture bears a heavy relationship—the charge of ethical imperialism is rightly extinguished. This is not to say that inadequate health care has been explicitly depicted as a cultural practice in Uganda, but rather that proponents of these tests have misidentified desperation for health care and the communal approval and support of local politicians and researchers as "cultural" factors to consider.

III. A PROPERTY ANALYSIS OF INFORMED CONSENT

A compelling way to look at informed consent would be to recognize the property interest an individual has in her body. Considering the recent dynamic scholarship on the broad scope of property as it relates to personhood and culture,[69] a strong argument can be made for using a property based theory of personhood as a more effective method of

---

[67] *Id.* at 99.

[68] *Id.*

[69] *See infra*, note 71.

approaching these situations.[70] Property law's construction of the body as an entity separate from the will has dramatic repercussions when considering who is given access to fungible property, e.g., drugs such as AZT, necessary for self-constitution. Thus, this Part will examine the potential for structuring the doctrine of informed consent around a theory of property law and assess its ability to better protect the bodily integrity of research subjects.

Recent theories, applying a property analysis to concepts such as race, consent to sexual intercourse, bodily organs, and cultural heritage and artifacts, have promoted broadening the scope of how the law conceives of property.[71] These theories share the common theme that property can shape and determine identity, and that by denying or restricting a property right, the law has both disembodied individuals and impaired one's essential personhood.

Professor Cheryl Harris ably explains the significance of identifying what constitutes property:

> Although the existence of certain property rights may seem self-evident and the protection of certain expectations may seem essential for social stability, property is a legal construct by

---

[70] Fueling this argument is the dilemma that the doctrine of informed consent for experiments conducted in developing countries, as advanced in the Declaration of Helsinki and the Nuremberg Code, is not legally binding. This dilemma has prompted one commentator to note that "the various declarations and codes defining ethical aspects of research on human subjects [are] really no more than pious hopes that doctors [will] behave ethically." *See* Nazi Doctors, *supra* note 63, at 160.

[71] *See* Cheryl Harris, Whiteness as Property, 106 Harv. L. Rev. 1709, 1729 (1993) (discussing whiteness as property); Alexandra Wald, What's Rightfully Ours: Towards a Property Theory of Rape, 30 Colum. J.L. & Soc. Probs. 459, 499 (1997) (discussing a property interest in a woman's right to consent to sex); Gregory S. Crespi, Overcoming the Legal Obstacles to the Creation of a Futures Market in Bodily Organs, 55 Ohio St. L.J. 1 (1994) (discussing the barriers to a recognized property right to one's bodily organs); and Rosemary J. Coombe, The Properties of Culture and the Politics of Possessing Identity: Native Claims in the Cultural Appropriation Controversy, *in* after identity: A Reader in Law and Culture 251 (discussing cultural appropriation of "voice" by telling "someone else's story"). While these theories have emerged relatively recently, theories espousing a broad conception of property date back to 1792 when Madison, in an essay entitled "Property," acknowledged that "[man] has property very dear to him in the safety and liberty of his person," and that "[h]e has an equal property in the free use of his faculties and free choice of the objects on which to employ them." While this view did not inform most of the following two centuries' conception of what constitutes legal property, nor, did it apply to anyone not enfranchised, it does demonstrate that property had conceptual roots beyond tangible, physical objects. *See* Laura S. Underkuffler, On Property: An Essay, 100 Yale L.J. 127, 135 (1990) (quoting Madison's essay "Property").

> which selected private interests are protected and upheld. In creating property "rights," the law draws boundaries and enforces or reorders existing regimes of power. The inequalities that are produced and reproduced are not givens or inevitabilities, but rather are conscious selections regarding the structuring of social relations.[72]

Professor Harris' analysis of legal consequences effected through property rightly exposes how a theory of property can disempower and disembody the individual not afforded property rights. In these HIV experiments it is apparent that the non-recognition of property rights manifests itself as the conscious choice by the researchers to reject individual entitlements for the utilitarian goal of maximizing social welfare. Facilitating this choice is adherence to traditional notions of property rights, which Professor Peter Halewood has criticized for their reliance on the "conceptual structure [of] the radical dichotomy between subject and object."[73] Because the classical liberal conception of property rights is founded on formal equality, Halewood explains, analyzing the process wherein liberal legalism has severed the concept of "will" (subject) from the "body" (object) is vital to understanding how current legal theory and practice affects socially and culturally diverse individuals: "The legal subject's isolation from object relations means that subjects can have no particular defining material characteristics. Thus, to make the formal equality of persons possible, liberalism defines persons in their most bare form, stripped of all particularity so that each possesses a similar moral weight."[74] In other words, liberal legalism is structured upon an "essentialist premise" that universalizes the human "will" by removing it from cultural contexts and circumstances, such as gender, race, or class.[75] The problem, then, is that the body is "reduced to the status of 'surplus' to human 'essence,'" or will; the effect is to extinguish the body's significance and relevance to "personhood" (the "free will" and "essence" of an individual human being).[76]

---

[72] Harris, *supra* note 71, at 1729-30.

[73] Peter Halewood, Law's Bodies: Disembodiment and the Structure of Liberal Property Rights, 81 Iowa L. Rev. 1331, 1340 (1996).

[74] *Id.*

[75] Melissa M. Perry, Fragmented Bodies, Legal Privilege, and Commodification in Science and Medicine, 51 Me. L. Rev. 169, 195 (1999).

[76] *Id.*

This criticism is very instructive in the context of these tests—especially when one considers the numerous references to the participants as test "subjects"[77]—because it exposes how the liberal dichotomy of body and will oppresses certain groups and facilitates a utilitarian justification of an experiment that exploits its participants. Because the body, Halewood argues, remains "essential to the construction of liberalism's account of rights—the unspoken referent from which the autonomous will is abstracted and with which it is contrasted," liberal legalism's conceptual dichotomy of will and body "impacts various groups differently, given the gendered and racialized identification of women and people of color with mere bodies and white men with pure wills. The erasure of the body in liberal legalism thus ensures the erasure of the female and racially 'other' subject while the white, male, autonomous 'universal' will, defined in opposition to the particularity of these 'other' subjugated wills and bodies, finds full expression and recognition in legal discourse." Thus, Halewood's account draws on feminist and critical race theories that posit that the notion of objectivity and formal equality in law has traditionally — and continues to — reinforce[78] existing distributions of power; it perpetuates the white male position of authority as the standpoint from which law interrelates to society.

Applying this analysis to the HIV tests, Halewood's argument posits an explanation for the willingness of the researchers to exploit the bodies of these women for an utilitarian goal. The emphasis on will—a myth in this context perpetuated by a dubious informed consent procedure—means that these women cannot protect their bodies because the body is controlled and protected by the will. Halewood contends, however, that by reincorporating the body into the scope of property through an "intersubjective approach" (similar to Volpp's intersectional analysis), which seeks a justification for rights and personhood beyond the subject/object dichotomy by emphasizing individual "situatedness" and the "primacy" of the body, one can better "identify the interests that properly should control in disputes over forms of property integral to personhood."[79] In other words, once the body is included in the liberal tradition of property rights as more than just the physical

---

[77] Many supporters of the tests cite the 1981 WHO/CIOMS Guidelines as authority for why these tests are ethical. *See supra* text accompanying notes 53-57. Notably, these Guidelines are entitled "International Ethical Guidelines for Biomedical Research Involving Human Subjects."

[78] Halewood, *supra* note 73, at 1378.

[79] *Id.* at 1380 and 1393.

boundary that protects the superior human "will," then protection of the body as a vital part of one's "personhood" can find expression as a property right.

Of course, one of the biggest concerns with recognizing property in one's body is the problem of commodification of that body. Numerous articles have been written on the "willingness" of indigents from developing nations to sell their kidneys, eyes, and other organs to wealthier persons in industrial countries.[80] Critics of the property approach to personhood and body parts argue that one of the traditional characteristics of property—alienability—would encourage a perverse marketplace that ultimately degrades those selling their body or body parts. While rightly demonstrating one concern of this property theory, the argument reveals a limited view of property as a symbol of power based on dominance. As one author posits, "If property rights are only the ability to say no, they resemble the conventional notions of power as a binary structure for control. However, if property rights take on the character of self-expression and protection, they take on the positive qualities [of power as empowering, energetic, and competent.]"[81] This perspective encourages a broader application of property law to personhood and body; it would emphasize the protective power of a property right over the alienability power. A crucial aspect of this argument, however, hinges on the recognition by other subjects of this property right. A property right in these women's bodies and personhood depends on the social recognition of those other subjects—those controlling the resources necessary to vindicate these rights.

Margaret Radin's theory that a right to property for personhood should be recognized in law — while open to criticism for some dubious assumptions she makes — offers a compelling theory on how to facilitate the acceptance/practice of this conception of property as empowering. Considering the importance of certain objects to self-constitution, or personhood, Radin suggests a radical redistribution of resources, premised on the idea of entitlements to property necessary for personhood. She writes:

> A welfare rights or minimal entitlement theory of just distribution might hold that a government that respects personhood must guarantee citizens all entitlements necessary for personhood. If the personhood dichotomy in property is taken

---

[80] *See, e.g.*, Gloria J. Banks, Legal & Ethical Safeguards: Protection of Society's Most Vulnerable Participants in a Commercialized Organ Transplantation System, 21 Am. J.L. & Med. 45 (1995); Stephen Ashley Mortinger, Spleen For Sale: Moore v. Regents of the University of California and the Right to Sell Parts of Your Body, 51 Ohio St. L.J. 499 (1990).

[81] Wald, *supra* note 71, at 499.

> as the source of a distributive mandate as part of such a general theory, it would suggest that government should make it possible for all citizens to have whatever property is necessary for personhood. But a welfare rights theory incorporating property for personhood would suggest not only that government distribute largess in order to make it possible for people to buy property in which to constitute themselves but would further suggest that government should rearrange property rights so that fungible property of some people does not overwhelm the opportunities of the rest to constitute themselves in property. That is, a welfare rights theory incorporating the right to personal property would tell the government to cease allowing one person to impinge on the personhood of another by means of her control over tangible resources, rather than simply tell the government to dole out resources.[82]

Radin's approach, applied to these tests, would require that the price of the drug AZT be reexamined as a "tangible resource" which allows the drug companies to "impinge" on the personhood of these women. The welfare-rights theory mandates the substitution of a market system which controls who gets access to life-saving drugs such as AZT for a system that mandates its distribution to all who need it to survive.[83] Her focus on the inseparable relationship of property to personhood in some contexts serves as a reminder that the recognition of property rights in one's body largely depends on access to the property necessary to sustain and self-constitute this body. This theory was echoed by one of the American critics of the tests, the President

---

[82] Margaret Jane Radin, Property and Personhood, 34 Stan. L. Rev. 957, 990 (1982) (citations omitted). While Radin's references to "government" suggest that her theory operates only on a national level, the international context of these experiments, a rapidly expanding global economy, and the universal effects and repercussions of the AIDS epidemic necessitate global application of this theory. *See, e.g.*, Dominguez-Urban, *supra* note 24, at 285-86 ("Considering the global effect of regulatory activity by producer nations, the international harmonization process needs to shift to a global outlook, and . . . require[s] that we recognize the interconnectedness of world health and research on health, particularly in the area of pharmaceuticals.").

[83] There is evidence that this approach is slowly gaining acceptance. Uganda is one of four countries (along with Chile, Vietnam, and Cote d'Ivoire) selected for a pilot program that "will help provide the health infrastructure and affordable drugs to ensure that combination therapies are used appropriately." AIDS Alert, *supra* note 52. It is reported that "[f]inancing will come from the pharmaceutical companies, which will sell the drugs at subsidized prices, from local health ministries, which will create new sources of funding, and from a $1 million grant from UNAIDS." *Id.*

of the Latino Commission on AIDS, when he expressed his outrage that these tests were being performed on people of color with no access to health care. Rather than performing these tests, he argued that the United States "should be using its power to negotiate lower drug prices."[84] Indeed, it appears that criticisms such as these have helped shift the focus of these debates toward a serious strategy to end the pharmaceutical corporations' virtual oppression of the developing world by setting drug prices at such a prohibitively high cost. The recipient of the 1999 Nobel Peace Prize, the humanitarian group Doctors Without Borders, has recently called for a "'health exemption for essential medicines that would allow poorer countries to mass-produce certain drugs cheaply without violating patent laws."[85] Efforts such as these should bring the welfare rights theory of property closer to reality for the millions of people currently deprived of vital health resources.

CONCLUSION

This focus on access to health care elicits strong comparisons and connections to the contextual roots of the Nuremberg Code's doctrine of informed consent—Nazi Germany. The doctrine formed as a response to the policies and practices of Nazi Germany regarding health care and medicine. The Nazi programs showed in macabre detail how medicine can be politicized and demonstrated how social and political constructions of those "bodies" in disfavored groups drive decisions of whose life is worthy of life-saving medicine and whose is not. The power of Halewood's analysis of liberal legalism's dangerous separation of body from will, Radin's welfare rights theory, and Volpp's antisubordination principle, lies in an understanding of how these approaches challenge the Nazi medical system, premised on the devaluation of certain bodies. Scrutinizing this relationship reveals how the use of a placebo for these subjects implicates the Nazi ideology that it is the destiny of these infected bodies to whither away.

One of the more striking facts about the Nazi regime is that doctors joined the party earlier and in greater numbers than any other group.[86] The ideology of the Nazi party easily lent itself to burgeoning concepts of racial

---

[84] *See* Mae M. Cheng, Group Decries AZT Placebo Use, Newsday, Oct. 3, 1997, at A45.

[85] Associated Press, "Doctor's Group Prods EU to Get Cheaper Drugs into Poor Nations," <http://cnn.com/HEALTH/9911/23/eu.trade.health.ap/index.html>. Visited Jan. 1, 2000. *See also* Mark Schoofs, The War *For* Drugs, The Village Voice, March 28, 2000, at 54.

[86] *See* Nazi Doctors, *supra* note 63, at 19.

medicine. The advent of sterilization laws—laws allowing for forcible sterilization of anyone suffering from a wide variety of diseases—and euthanasia laws were early indicators that Nazi medical policies were aimed at eliminating those considered "infected" or not "racially valuable."[87] The propaganda for these laws, advanced during an acute shortage of funds in health services during Germany's Great Depression, were characterized in terms of the sterilization of the "inferior" and the elimination of "unnecessary eaters."[88] One commentator has connected these laws to the "final solution" through the "important theoretical link [which] might be called the 'medicalization of anti-Semitism,' part of a broader effort to reduce a host of social problems—unemployment, homosexuality, crime, 'antisocial behavior,' and others—to medical, or, ideally, surgical problems."[89] Indeed, the linking of science and medicine to the racist ideology of the Nazi party demonstrates the power of politicizing medicine and regulating its access to those considered unworthy.

The Nazi party's construction of the Jewish body as "diseased" and inferior fed directly into their medical policies. Sander Gilman, describing the evolution of this construction, states that "[b]y the nineteenth century, with the establishment of the hegemony of 'science' within Europe (and colonial) culture, there is no space more highly impacted with the sense of difference about the body of the Jew than the public sphere of 'medicine.'"[90] The connection between the perception of the Jewish body as impure and contaminated and the complicity of German doctors in the Nazi effort to destroy the lives of an entire people is essential to understanding the underlying context of the doctrine of informed consent: This doctrine is a response against the view that certain groups are not worthy of medicine or bodily integrity because of social or political construction of their bodies as inferior.

---

[87] *Id.* at 22. A significant point to note concerning Germany's racialized medicine is that the United States provided the most important model for its sterilization laws. German racial hygienists "expressed their envy of American achievements in this area, warning that unless Germans made progress in this field, America would become the world's racial leader." *Id.* at 21.

[88] *Id.* at 39.

[89] *Id.* at 25 (emphasis omitted).

[90] Sander Gilman, The Jew's Body 38 (1991).

The legacy of Nazi Germany's construction (and destruction) of the Jewish race has profound effects on how American health agencies and most Westerners view the crisis in Africa and the other sites of these tests. While the Nazi experience was by no means the first historical example of persecution of the perceived "other," it does stand out as one of the most dramatic examples of the compliant role science plays in the annihilation of the "other." Considering this concept of racialized medicine and the construction of the body, these tests in Africa take on a more compelling urgency. To be sure, the African body has largely been depicted in postcolonial media images as diseased, dismembered, deformed, and deceased.[91] The familiar images of famine victims and piles of Rwandan corpses framed by headlines announcing staggering numbers dead and dying in yet another part of Africa have informed and defined the African body for most Americans. The pictures blend so easily into one another, erasing the individual while emphasizing a notion that these bodies are irrelevant. Thus, our own construction of the African body, like the Nazi construction of the Jew, compels and informs the apathy shown the medical holocaust now occurring in these nations.[92] In this sense, Halewood's argument that the body needs to be reincorporated into the scope of property takes on the added dimension of acknowledging the process wherein these bodies have been distorted and debased. This perspective cannot, and should not, be severed from an analysis of the market price of AIDS drugs and the inability of some "bodies" to access them. If a property interest analysis of one's body can combat the notion that some persons are not worthy of medicine such as AZT, in the sense that their inability to afford it is a justification, then the doctrine of informed consent's essential purpose—the bodily integrity of all persons—will have been realized.

---

[91] Considering this perspective of the foreign body as diseased in the time of AIDS, law professor Alan Hyde notes that "[t]he body politic, the general 'public' so familiar to us from contemporary discussions of AIDS, purifies itself by identifying, specularizing, and abjecting the foreign, polluting Other." Alan Hyde, Law's Bodies 250 (1997). Hyde's observation is strengthened when one considers the popular stereotype that abounds in the West that AIDS began in Africa from men and women having sex with infected monkeys. *See* Gilman, *supra* note 91, at 225. These types of crude beliefs encourage the notion that these female participants either deserve to be infected, or, only slightly less hostile, do not experience any real loss by being infected relative to everyone else in Africa.

[92] One author has stated that "Africa is reeling from an epidemic of Biblical proportions," and that "AIDS is on track to dwarf every catastrophe in Africa's recorded history." Mark Schoofs, AIDS: The Agony of Africa, The Village Voice, Nov. 9, 1999, at 40. Schoofs reports that the virus has already killed more than 11 million sub-Saharan Africans, and that more than 22 million others are infected.