

# Essay

## PAYING FOR SUFFERING: THE PROBLEM OF HUMAN EXPERIMENTATION

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### INTRODUCTION

Several years ago, I had the privilege of working with David Feldshuh and Daniel Booth, colleagues of mine at Cornell University, in the production of an educational video, *Susceptible to Kindness: Miss Evers' Boys and the Tuskegee Syphilis Study*.<sup>1</sup> The video examines the ethical issues raised by the infamous experiment, the Tuskegee Study of Untreated Syphilis in the Negro Male (Tuskegee Study).<sup>2</sup> David Feldshuh's award-winning play, *Miss Evers' Boys*,<sup>3</sup> is a fictionalized account

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On May 16, 1997, President Clinton formally apologized on behalf of the federal government for the Tuskegee Experiment. 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 A1, available in 1997 WL 10693767. Five of the eight living victims of the Experiment attended the White House ceremony. See *id.* The President told them: "We can stop turning our heads away, we can look at you, in the eye, and finally say, on behalf of the American people, what the United States government did was shameful, and I am sorry." *Id.*

1. SUSCEPTIBLE TO KINDNESS: MISS EVERS' BOYS AND THE TUSKEGEE SYPHILIS STUDY (1994) [hereinafter SUSCEPTIBLE TO KINDNESS].

2. See FINAL REPORT OF THE TUSKEGEE SYPHILIS STUDY AD HOC PANEL TO THE DEPARTMENT OF HEALTH, EDUCATION AND WELFARE (1973) [hereinafter FINAL REPORT OF THE TUSKEGEE SYPHILIS STUDY].

The Tuskegee Study of Untreated Syphilis in the Negro Male was a forty-year study (1932 to 1972) conducted by the United States Public Health Service to document the long-term effects of syphilis. The study tracked some 400 men from Macon County, Alabama, by charting their health via annual medical exams and by performing autopsies on the more than 100 men who died over the course of the study. The men were never told that they were subjects of a study, nor were they ever told the exact nature of their disease.

The subjects, mostly tenant farmers in rural Macon County, were originally gathered to receive free medical treatment.

LARRY I. PALMER, STUDY GUIDE FOR DISCUSSION LEADERS, SUSCEPTIBLE TO KINDNESS: MISS EVERS' BOYS AND THE TUSKEGEE SYPHILIS STUDY (1994) (accompanying the video). For a detailed account of the study, see JAMES H. JONES, BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT (1993).

3. DAVID FELDSHUH, MISS EVERS' BOYS (1995).

of the Tuskegee Study,<sup>4</sup> which was conducted by the United States Public Health Service from 1932 to 1972.<sup>5</sup> Daniel Booth, a filmmaker, created the juxtaposition of selected scenes from a performance of *Miss Evers' Boys* at Cornell University, interviews with commentators, historical film footage, music, and photographs, which became the "text" of our prize-winning video.<sup>6</sup> I was the executive producer and author of the written study guide that accompanies the video.<sup>7</sup> The educational video and study guide focus on a number of issues, including personal and professional ethics, the relationship between law and medicine, and the social forces of race, gender, and economic status in shaping what may be right or good when power and authority are variously defined.<sup>8</sup>

The selected title, *Susceptible to Kindness*, serves as a metaphor for the human tragedy of the Tuskegee Study. The metaphor comes from a scene near the end of the play, *Miss Evers' Boys*, in which Miss Evers is testifying before a United States Senate Committee consider-

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4. The play was inspired by David Feldshuh's reading of Jones's *Bad Blood: The Tuskegee Syphilis Experiment*, JONES, *supra* note 2, and other primary sources about the Study during his completion of his residency training in emergency medicine. Feldshuh had previously earned a Ph.D. in theater. The protagonist of Feldshuh's play, Miss Evers, is based on a real public health nurse, Eunice Rivers, whose voice and photograph are a part of the video. See *SUSCEPTIBLE TO KINDNESS*, *supra* note 1. The other characters in the play are four African-American tenant farmers; Dr. Douglas, a Caucasian public health physician; and Dr. Brodus, the African-American head of the hospital at Tuskegee Institute. FELDSHUH, *supra* note 3. The play premiered at the Center Stage in Baltimore, Maryland in November 1989 and has been performed at many theaters throughout the country. *Miss Evers' Boys* won the Gerald R. Dodge Foundation's New American Play Award in 1989 and was nominated for the Pulitzer Prize in 1992. Home Box Office (HBO) produced a film version of the play, which originally aired on February 22, 1997. The play was first published in *American Theatre* in November 1990. See David Feldshuh, *Miss Evers' Boys*, 7 AM. THEATRE, Nov. 1990 (special pull-out section).

5. See FINAL REPORT OF THE TUSKEGEE SYPHILIS STUDY, *supra* note 2.

6. The video won four awards: a CINE Golden Eagle in 1994 as a "documentary"; a Gold Plaque Award in the "Politics, Society, and Government" category in the International Communication Film & Video Festival, INTERCOM '94; Best of Category, "Issues and Ethics" in the International Health & Medicine Film Festival, 1994; and a Silver Apple in "The Health Issues and Ethics" category in the 1995 National Educational Media Competition.

7. See PALMER, *supra* note 2. The text of the study guide was a commentary on the artistic creation of Daniel Booth. Collaborating with two artists seeking to contribute to the public discourse on human experimentation required me to use "literary imagination." See MARTHA C. NUSSBAUM, POETIC JUSTICE: THE LITERARY IMAGINATION AND PUBLIC LIFE 2-3 (1995) (positing that the imagination writers use to create literature will guide societal development because their ideas will be read by and affect the minds of judges, legislators, and policymakers). As noted in the study guide: "The educational value of *Miss Evers' Boys* lies in the intersection between the moral vision within the play and the very strong reactions of those who view the play as a description of social or inner reality." PALMER, *supra* note 2, at 3.

8. See PALMER, *supra* note 2, at 11-20.

ing legislation concerning research on human subjects.<sup>9</sup> Justifying her role in the forty-year Study, Miss Evers declares: "I loved those men . . . [they] were susceptible to kindness."<sup>10</sup>

The Tuskegee Study reappears periodically in public discourse, most recently in 1995 when President Clinton's nominee for Surgeon General, Dr. Henry Foster, Jr., was alleged to have participated in the Study.<sup>11</sup> Dr. Foster's critics, and even some scholars, have questioned whether he knew of the Tuskegee Study when he was a practicing physician in Tuskegee in 1969. The nagging questions about Dr. Foster suggest that there are important lessons to learn from reexamining the Study, even twenty-five years after a panel of experts made recommendations that they believed would prevent future abuses of patients or subjects.<sup>12</sup>

The Tuskegee Study acts as precedent even though there is no traditional case law involving the Study.<sup>13</sup> Tuskegee's legacy is

9. FELDSHUH, *supra* note 3, at 93.

10. *Id.* at 97.

11. See JONES, *supra* note 2, at 209 (stating that as early as February 1969, during Dr. Foster's vice presidency of the Macon County Medical Society, the organization voted unanimously and without comment to refer the Study to the Macon County Health Department); *Foster Quizzed on Tie to Experiment*, COM. APPEAL (Memphis), Feb. 25, 1995, at 2A, available in 1995 WL 2642106; David L. Kirp, *Blood, Sweat, and Tears: The Tuskegee Experiment and the Era of AIDS*, TIKKUN, May 1995, at 50, available in 1995 WL 12580337; Lisa Nevans, *Foster Says Race Plays Part in Attacks, Finds Pattern in Opposition*, WASH. TIMES, Mar. 17, 1995, at A1, available in 1995 WL 2558782. Although the Family Research Council, based solely on Jones's account, charged Dr. Foster with knowledge of the Study, a member of the Council conceded that Jones's book neither places Dr. Foster at that meeting nor claims that he was aware of the experiments. See *Foster Didn't Know Anything About the Tuskegee Experiment* (National Public Radio broadcast, Feb. 25, 1995). Moreover, Fred Gray, attorney for the subjects, has stated that his investigation did not indicate that Dr. Foster had any knowledge of the Study while it was being conducted. See *id.*

12. See FINAL REPORT OF THE TUSKEGEE SYPHILIS STUDY, *supra* note 2, at 23-47.

13. Society seems to have accepted that something "bad" happened during the Tuskegee Study, but some scholars have taken great literary license with the facts. For instance, Jack Kevorkian, the outspoken proponent of legalizing physician assistance in dying and a longtime advocate of allowing experimentation on prisoners condemned to death, stated the following about the Tuskegee Study:

The wartime medical crimes [referring to the Nazi concentration-camp experiments] were one result. The ethical sickness had spread to the United States even before World War II, but evidence of it surfaced only after the war, when in 1981 a horrible experiment on syphilis in Tuskegee, Alabama, was described in detail. It involved a *nontherapeutic* study of 399 syphilitic black prisoners and 201 uninfected black prisoners who served as "controls." None of the subjects was asked their consent or knew what was happening.

JACK KEVORKIAN, *PRESCRIPTION MEDICIDE: THE GOODNESS OF PLANNED DEATH* 170 (1991) (citations omitted). In his zeal to argue the inadequacy of the modern code of ethics for human experimentation, Kevorkian might have ignored the difference between tenant farmers and prisoners in describing what in fact happened in the Tuskegee Study.

grander because it was a stimulus to the current model of regulating human experiments—the “institutional review board”<sup>14</sup>—and the prevailing model of professional ethics, which is grounded in a subject’s consent.<sup>15</sup> Within this model, monetary compensation is often proffered as a solution after a subject is injured or killed in the course of human research,<sup>16</sup> or when it is discovered that an individual did not consent to being the subject of human research.<sup>17</sup> After a lawsuit was filed in 1974,<sup>18</sup> the federal government agreed to compensate the subjects of the Tuskegee Study.<sup>19</sup> Examining the terms of this settlement will make society less willing to embrace the concept that paying for suffering resolves the deep public policy issues that human experimentation presents.

The Tuskegee legacy has also helped to shape the latest government report on human experimentation, the *Final Report of the Advisory Committee on Human Radiation Experiments*.<sup>20</sup> This Report suggests

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Another explanation for the creative license taken with the facts of the Tuskegee Study is that issues associated with race are easily distorted. See NUSSBAUM, *supra* note 7, at 93-97 (discussing the effects of a reader’s race on his ability to judge Bigger Thomas’s thoughts and actions in Richard Wright’s *Native Son*). Feldshuh, for instance, has mentioned in conversations with this Author that he has encountered African-American actors who have stated categorically that the government actually “gave” syphilis to the tenant farmers in Macon County.

14. See generally 42 U.S.C. § 289 (1994) (providing that any entity applying for a federal government biomedical research grant for studies that use human subjects must establish a review board “to protect the rights of the human subjects of such research”).

15. See ARTHUR CAPLAN, IF I WERE A RICH MAN COULD I BUY A PANCREAS?: AND OTHER ESSAYS ON THE ETHICS OF HEALTH CARE 94 (1992) (listing the duties of research institutions to obtain informed consent from human subjects); JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT 59-84 (1984) (discussing the development of informed consent); LARRY I. PALMER, LAW, MEDICINE, AND SOCIAL JUSTICE 43-44 (1989) (discussing the social and legal importance of informed consent); DAVID J. ROTHMAN, STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING 93 (1991) (describing the Food and Drug Administration’s (FDA) definition of informed consent and its historical origins).

16. See *Student’s Death Is Linked to an Anesthetic*, N.Y. TIMES, Apr. 5, 1996, at B4. A nineteen-year-old volunteer in a study on the effects of smoking and air pollution died after an accidental overdose of topical anesthetic during a lung test. See *id.* The woman’s family said it planned to file a \$100 million lawsuit against the hospital. See *id.*

17. See *Mink v. University of Chicago*, 460 F. Supp. 713, 716-18 (N.D. Ill. 1978) (finding that pregnant women were unknowingly administered diethylstilbestrol (DES) as part of a university study of the drug’s effectiveness in preventing miscarriages).

18. See Plaintiff’s Complaint, *Pollard v. United States*, 384 F. Supp. 304 (M.D. Ala. 1974) (No. 4126-N).

19. See JONES, *supra* note 2, at 217-19.

20. FINAL REPORT OF THE ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS (1996).

that Congress should provide monetary damages to unknowing participants in studies conducted over the last fifty years.<sup>21</sup>

Given the specifics of the *Final Report of the Advisory Committee on Human Radiation Experiments*, it is apparent that the legal response to the Tuskegee Study provided the Radiation Committee with a framework in which monetarily compensating "victims" of modern medical progress is accepted as the appropriate governmental response.<sup>22</sup> Despite the similarity between the government's response to the Tuskegee Study and the Human Radiation Experiments, providing governmental compensation to victims is only one of several alternative responses to the persistent public policy problem of human experimentation.<sup>23</sup> In fact, other responses must be considered as we move toward a conceptualization of the appropriate social functions of science, medicine, and law.

In reviewing the Tuskegee Study for institutional lessons, commentators must resist the prevailing view that the physicians and scientists involved in the Study were bad or even racist; this view blinds scholars to the ineffectiveness of our present legal response to human experimentation.<sup>24</sup> Although society may not be susceptible to the kindness of a caring public health nurse such as the fictionalized Nurse Evers,<sup>25</sup> it may be susceptible to a religious-like faith in medical progress and legal utilitarianism when confronting human suffering.<sup>26</sup>

#### I. THE TUSKEGEE STUDY: COMPENSATION BY SETTLEMENT

After the Tuskegee Study became the subject of media reports, Fred Gray, who has had a long history of involvement in civil rights

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21. *Id.* at 512. The Radiation Committee recommended financial compensation for the subjects (or their surviving immediate family members) for whom the experiments provided no prospect of direct medical benefit or who had been misled into believing that controversial interventions were actually standard practice. *Id.* at 513. Furthermore, the Committee recommended that the compensation be adequate to cover relevant medical expenses and associated harms, including pain and suffering, loss of income, and disability. *Id.*

22. See FINAL REPORT OF THE ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS, *supra* note 20, at 178-88.

23. See CAPLAN, *supra* note 15, at 70-99; JAY KATZ, EXPERIMENTATION WITH HUMAN BEINGS: THE AUTHORITY OF THE INVESTIGATOR, SUBJECT, PROFESSIONS, AND THE STATE IN THE HUMAN EXPERIMENTATION PROCESS 248-52 (1972); ROTHMAN, *supra* note 15, at 248.

24. See Statement by Committee Member Jay Katz, FINAL REPORT OF THE ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS, *supra* note 20, at 849-56 (criticizing current regulation of human experimentation); see also PALMER, *supra* note 2, at 14 (discussing the need to understand the relationship of health care to economic resources as a means to avoid "simplistic perspectives on our present health care crisis").

25. FELDSHUH, *supra* note 3.

26. See CAPLAN, *supra* note 15, at 243; KATZ, *supra* note 23, at 598.

litigation,<sup>27</sup> filed a lawsuit on behalf of the survivors of the Study and the heirs and representatives of the participants who had since died.<sup>28</sup> With the assistance of lawyers from the NAACP Legal Defense Fund,<sup>29</sup> Gray named as defendants the United States Government, the United States Public Health Service, the United States Center for Disease Control, the United States Department of Health, Education and Welfare, Department officials in their professional capacities, the State of Alabama, a private foundation, and individual physicians working for the United States Public Health Service.<sup>30</sup>

The complaint, filed in the United States District Court for the Middle District of Alabama, alleged that the defendants' conduct violated the constitutional rights of the survivors and the deceased participants in the experiments.<sup>31</sup> The complaint also requested that each survivor or decedent representative be awarded \$1.5 million as compensation for the deprivation of their constitutional rights.<sup>32</sup>

Gray's legal theory was that the tenant farmers selected for the Study by the Public Health Service were chosen solely because they were African American.<sup>33</sup> As a consequence of this reasoning, Gray did not name as defendants any of the African-American physicians or nurses involved in the Study.<sup>34</sup> Under Gray's conception, the victimization of these African-American nurses and physicians by a racially

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27. Gray is well known as the lawyer who represented Rosa Parks, whose arrest precipitated the Montgomery Bus Boycott in 1955. *See Parks v. City of Montgomery*, 92 So. 2d 683 (Ala. Ct. App. 1957).

28. *See Plaintiff's Complaint*, *Pollard v. United States*, 384 F. Supp. 304 (M.D. Ala. 1974) (No. 4126-N).

29. *See id.* at 14.

30. *See id.* at 1-2.

31. *See id.* at 12.

32. *See id.* Plaintiffs filed suit under 42 U.S.C. § 1983, seeking damages for deprivation of rights under color of law. *See Plaintiff's Complaint* at 2, *Pollard* (No. 4126-N).

33. *See Plaintiff's Complaint* at 10-11, *Pollard* (No. 4126-N). Paragraph 13 of the Complaint stated:

The subjects of the study were racially selected: only black men were used as subjects in the study. . . . Plaintiffs allege that the black subjects were selected and used in the experiment, a program of controlled genocide solely because of their race and color in violation of their rights, secured by the Constitution and Laws of the United States.

*Id.*

34. *Id.* at 1. In his book, *Bad Blood: The Tuskegee Syphilis Experiment*, James Jones writes: The Tuskegee Institute, for which Gray served as the general counsel, was not named in the suit. Neither was the Veterans Hospital. The local health department and the Macon County Medical Society also escaped legal notice. In fact, no predominantly black institution was named in the suit. The same was true of individuals; all of the individually named defendants were white. No black physicians were mentioned; neither were any black nurses.

JONES, *supra* note 2, at 216.

segregated medical profession and society mitigated their legal culpability.<sup>35</sup> He believed that race had a greater explanatory force than notions of professionalism, which might have encompassed both the Caucasian and African-American professionals over the forty-year period of the Study.<sup>36</sup> After numerous pretrial maneuvers, the lawyers for the plaintiffs and the United States Government reached a monetary settlement in which each surviving subject received \$37,500, each heir or representative of a deceased subject received \$15,000, each of the "controls" received \$16,000, and the heir or representative of each control received \$5,000 from the \$10 million settlement paid by the federal government.<sup>37</sup>

In retrospect, Gray's theory of racial selection as the starting point for a legal analysis of human experimentation seems unwise. His theory fails to account for the importance of institutional arrangements as an explanation of what happened to his clients<sup>38</sup>—the Caucasian public health physicians named as defendants in the lawsuit relied upon African-American physicians to refer syphilitic patients to the Public Health Service for over forty years.<sup>39</sup> These African-American physicians should at least be viewed as co-investigators, rather than as anonymous African-American professionals victimized by "the system."<sup>40</sup> Were any of these local physicians subject to suits for malpractice based on their failure to offer penicillin as a treatment option after it was discovered to be a cure for syphilis?<sup>41</sup> Although the "lack of informed consent doctrine"<sup>42</sup> had not yet been developed,<sup>43</sup> the lingering questions about Dr. Foster<sup>44</sup> and one of Feldshuh's fictional characters in *Miss Evers' Boys*, Dr. Brodus,<sup>45</sup> help to shed light on how the dynamics of science and medicine influence professional perspectives on the ethics of using human subjects.

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35. See JONES, *supra* note 2, at 216.

36. See *id.*

37. See *id.* at 217.

38. See NEIL K. KOMESAR, *IMPERFECT ALTERNATIVES: CHOOSING INSTITUTIONS IN LAW, ECONOMICS, AND PUBLIC POLICY* 210-15 (1994) (describing institutional analyses of race-related issues).

39. See JONES, *supra* note 2, at 114-15, 136-38.

40. See *id.* at 144-47.

41. See PALMER, *supra* note 15, at 23 (noting that physicians are bound to treat patients based upon the level of knowledge, care, and skill of an average physician in similar circumstances); see also ROTHMAN, *supra* note 15, at 183 (criticizing the explanation of the Study's doctors for failing to treat syphilis with penicillin after 1945).

42. See *supra* note 15 and accompanying text.

43. See KATZ, *supra* note 15, at 59-80 (stating that the lack of informed consent doctrine took form in the late 1950s).

44. See *supra* notes 11-12 and accompanying text.

45. See *supra* note 4.

A. *Good People, Bad Institutional Arrangements?*

In a scene from the play, *Miss Evers' Boys*, Dr. Brodus, the administrator and head of the hospital at the Tuskegee Institute, examines one of the men in the Study—one of Miss Evers' Boys—in 1946 after penicillin had been discovered.<sup>46</sup> Both Nurse Evers and Dr. Douglas, the Caucasian physician from the United States Public Health Service, are present and participate in various conversations about whether, after fourteen years, the men should be given the choice of using penicillin for their advanced stages of syphilis.<sup>47</sup> On the one hand, Dr. Brodus is somewhat of a modern hero when he questions Dr. Douglas about the desirability of allowing the men to decide for themselves whether to take the risks of using penicillin for their advanced syphilis.<sup>48</sup> On the other hand, when he is questioned by Nurse Evers, Dr. Brodus uses a form of racial and professional paternalism to justify continuation of the Study without telling the men about the availability of penicillin.<sup>49</sup> When Nurse Evers pleads on behalf of the tenant farmers, Dr. Brodus shouts back in anger: "You think you're the only person who feels? You got your burden and I got mine. You serve the race in your way. I serve it in mine. I can't rock the boat while I'm trying to keep a people from drowning."<sup>50</sup>

It is apparent that Dr. Brodus is concerned about future funding for his hospital, one of the few resources of modern health care for African Americans in his community. He is also concerned about his role as a research scientist to his liberal (by mid-1940s standards) colleague, Dr. Douglas.<sup>51</sup> It is also apparent that Dr. Brodus has a highly individualistic vision of his social role. While some commentators in the video, *Susceptible to Kindness: Miss Evers' Boys and the Tuskegee Syphilis Study*, see Dr. Brodus as caught up in the system, others suggest that the socioeconomic difference between him—an educated professional—and the patients—illiterate tenant farmers—prevents him from seeing the possible harm to the individual patients.<sup>52</sup> In some respects, Drs. Brodus and Douglas are like many modern professionals—unable to sort out how the mixture of personal and profes-

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46. FELDSHUH, *supra* note 3, at 71-77.

47. *Id.*

48. *Id.* act II, sc. vii.

49. *Id.*

50. *Id.*

51. The fictional Caucasian doctor, Dr. Douglas, was based upon Dr. John Cutler, Professor Emeritus at the University of Pittsburgh Graduate School of Public Health and a physician in the United States Public Health Service from 1947 to 1967. Dr. Cutler served as one of the commentators in our video. See PALMER, *supra* note 2, at 22.

52. FELDSHUH, *supra* note 3, at 97.



sional ethics, and perhaps professional ambition, influences their decisions.

The four hundred African-American males involved in the Tuskegee Study were originally gathered at the beginning of the Great Depression to receive free medical treatment for syphilis.<sup>53</sup> The United States Public Health Service and a private philanthropy created a partnership<sup>54</sup> to bring some measure of health care to rural African Americans in the then-prevailing practice of fee-for-service medicine.<sup>55</sup> The individual within the Public Health Service who decided that monitoring the men was appropriate once foundation funds were no longer available is unknown. In the play, *Miss Evers' Boys*, Dr. Douglas is at least idealistic in the sense that he tries to save the treatment program in 1932 after the funds are withdrawn.<sup>56</sup> He is professionally committed to providing health care services to the most underserved population of his day.<sup>57</sup> For many years, no one among his professional colleagues questioned the appropriateness of Dr. Douglas's actions. Although no moral conflict is apparent in Dr. Douglas's character, if we try to imagine ourselves in a totally segregated society, would any of us necessarily have experienced moral conflict at the time?

The fictional Nurse Evers helps us to recall that prior to the discovery of penicillin, syphilis was classified as a "chronic illness."<sup>58</sup> At that time, popular culture had not yet become infused with the modern notion that every human affliction, such as cancer, multiple sclerosis, lupus, diabetes, and AIDS, is subject to cure. Currently, new treatments that prolong life or ameliorate the symptoms of those with chronic illnesses only reinforce the notion that a cure is just around the corner. Research on diet, violence among youth, or the Ebola virus in Zaire only encourages the belief that science can stop these epidemics and provide solutions to these current plagues.

It would be a mistake simply to focus on Nurse Rivers because of her continuity with the Tuskegee Study or because her role has been artistically immortalized through the character of Nurse Evers in *Miss Evers' Boys*. Trying to imagine the ethical dilemmas from her perspec-

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53. See JONES, *supra* note 2, at 116-19.

54. In the early 1930s, the Julius Rosenwald Fund provided the funds necessary for determining whether syphilis was treatable. See *id.* at 54-60.

55. See *id.*

56. FELDSHUH, *supra* note 3, act I, sc. v.

57. African Americans and other minority groups are still underserved by the medical profession today. See Miriam Komaromy et al., *The Role of Black and Hispanic Physicians in Providing Health Care for Underserved Populations*, 334 NEW ENG. J. MED. 1305, 1305 (1996).

58. FELDSHUH, *supra* note 3, act II, sc. ii.

tive does, however, shed light on the institutional arrangements among science, medicine, gender, race, and law over time.

Our ethics-starved modern minds reason that the discovery in the 1940s of penicillin as a cure for syphilis required public health officials to provide treatment to all of the men in the Tuskegee Study. For those public health workers who had labored for years to provide some care to the medically neglected, however, the miracle drug had yet to be tested in the reality of medical practice in the rural America of the Deep South—a reality that would today be labeled as a problem of “access” to health care services. For the public health care workers servicing a portion of the public not yet infused with the dreams of scientifically based medicine, the risks of penicillin loomed much larger than its benefits.<sup>59</sup> This wholly paternalistic vision of the professionals’ right to decide the hard ethical questions for “their” patients was not incompatible with the ethos of the entire profession prior to the mid-1960s.<sup>60</sup>

### *B. Institutional Lessons*

The first lesson to learn from the Tuskegee experiment is a cautionary one. Before commending or condemning professional behavior, we should better understand the forces, particularly the conceptions of knowledge, that drive professional behavior. One of these forces is the belief that understanding the nature of disease and its transmission helps determine the optimal use of health resources.<sup>61</sup> We all benefit from continued drug research; in plain terms, we now know that penicillin and other antibacterial drugs change the nature of bacteria, which requires new antibacterial drugs. Today, the methods for investigating the effectiveness of drugs and disease progression involve research on viruses, bacteria, and genes using methodologies that were simply unknown sixty years ago. Research may involve using certain populations to aid scientists’ efforts to isolate the molecular or genetic nature of breast cancer or alcoholism, for example, or to determine why some isolated populations have certain incidences of disease.<sup>62</sup> Because of the nature of scientifically based medicine, research involving human subjects will continue.

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59. See JONES, *supra* note 2, at 8.

60. See ROTHMAN, *supra* note 15, at 101-26.

61. See PALMER, *supra* note 15, at 8.

62. See, e.g., Jonathan E. Kaplan et al., *Workup on the Waoroni*, NAT. HIST., Sept. 1984, at 68 (discussing isolated South American natives who apparently are free from cancer and heart disease); Craig D. Rose, *Taking Aim at Asthma Secrets: Sequana, Canadian Team Seeking to Unlock Genetic Code in Work with Isolated Population*, SAN DIEGO UNION-TRIB., Sept. 22, 1994,

Perhaps we have become so accustomed to the possible health care benefits of genetic research that we sometimes fail to understand the complex ethical dilemmas associated with modern scientific research. The recently reported higher incidence of diabetes among African Americans<sup>63</sup> led to speculation that there may be a genetic "cause" of diabetes.<sup>64</sup> In our zest to find cures in these discoveries, alternative explanations—for example, that the high incidence of diabetes is due to environmental conditions of the fetus and thus correlates with the mother's social and economic status—are nearly drowned out of public discourse.<sup>65</sup> Compared with the ethical quandaries of biotechnological developments, the Tuskegee Study, in retrospect, appears simple.

The other lesson for science and medicine is easy to state, but difficult to explain. Most scientists and professionals are ambivalent about the relationship of race to their work. The Tuskegee researchers wanted to know if syphilis took a different course in African Americans than in Caucasians.<sup>66</sup> Lurking underneath that line of inquiry was whether biological differences among races meant that the medical response to the individual patient should consider this demographic factor. Lest we label as "racists" the researchers who might have asked those questions, we should recall how reluctant modern scientists are to admit that forensic DNA data are kept by race<sup>67</sup> or

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at C1, *available in* 1994 WL 5443636 (discussing isolated island population with an extremely high asthma rate).

63. See Sarah L. Roberts, *Cracking the Code*, DIABETES FORECAST, Aug. 1994, at 60, 60.

64. Great advancement in the understanding of the genetic nature of diabetes has led to the production of genetically engineered human insulin. See ROBERT POLLACK, *SIGNS OF LIFE: THE LANGUAGE AND MEANINGS OF DNA* 110 (1994). Such advancements, however, can raise serious concerns:

In the absence of clear legal boundaries, we are at risk of developing a de facto national eugenics policy after all, not because we wish to identify and then eliminate people as undesirable members of "lesser races," but because some alleles will be considered undesirable by organizations in a position to limit their replication.

*Id.*

65. See *id.* at 9.

66. See JONES, *supra* note 2, at 27-28.

67. After a DNA sample is obtained and matched to that of a criminal suspect, the final step in compiling forensic DNA evidence is to determine the statistical probability that the crime scene sample came from someone other than the suspect. See Ranajit Chakraborty & Kenneth Kidd, *The Utility of DNA Typing in Forensic Work*, 254 SCI. 1735, 1736 (1991). Each band in the sample is measured for its frequency of occurrence within a database composed of persons of a given race; these databases are composed of samples from hundreds of unrelated individuals subdivided by ethnic group, such as Caucasian, African American, and Hispanic. See *People v. Barney*, 10 Cal. Rptr. 2d 731, 736-37 (Ct. App. 1992); *People v. Simpson*, No. BA 097211, 1995 WL 313118 (Cal. Super. Ct. L.A. County 1995); *People v.*

that the debate about the social policy implications of race continues today.<sup>68</sup>

Finally, the Tuskegee experiment sends a clear message to lawyers: they must become "reflective practitioners"<sup>69</sup>—active legal minds that continually question the institutional frameworks that are brought to problems.<sup>70</sup> Like most lawyers trained in the common law tradition, Fred Gray, in his representation of those harmed by the Tuskegee Study, was not equipped with an institutional analysis that would have allowed him to consider science and medicine as powerful institutional forces. Gray may not even have considered whether the growth of medicine and science might require the development of new legal concepts. He might not, for example, have considered whether naming individual practicing physicians, who happened to have been African American, as defendants might have *enhanced* his

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Wesley, 533 N.Y.S.2d 643, 658 (Co. Ct. 1988), *aff'd*, 589 N.Y.S.2d 197 (App. Div. 1992), *aff'd*, 633 N.E.2d 451 (N.Y. 1994).

In 1991, a debate arose within the scientific community as to whether databases should be maintained by narrower racial categories. Under the Lewontin and Hartl "substructuring" theory, the three broad, homogeneous populations named above do not mate randomly, influencing their degree of genetic variation. See Richard C. Lewontin & Daniel L. Hartl, *Population Genetics in Forensic DNA Typing*, 254 SCI. 1745, 1747 (1991). Accordingly, genetic databases of Hispanics, for example, must be subdivided into groups such as Mexicans and Puerto Ricans. This controversial hypothesis was quickly debunked, see 1A U.S. DEPT. JUSTICE, FBI REP., VNTR POPULATION DATA: A WORLDWIDE STUDY 2 (1993); Chakraborty & Kidd, *supra*, at 1738-39, and abandoned by its original proponents. See Daniel L. Hartl & Richard C. Lewontin, *DNA Fingerprinting Report (Letter)*, 260 SCI. 473 (1993). Citing the FBI study, a California court held that substructuring has a negligible effect on forensic DNA statistical evidence. See *People v. Soto*, 35 Cal. Rptr. 2d 846, 859 (Ct. App. 1994); see also Paul B. Tyler, *The Kelly-Frye "General Acceptance" Standard Remains the Rule for Admissibility of Novel Scientific Evidence*, 22 PEPP. L. REV. 1274, 1288-1300 (1995) (discussing the debunking of the theory that substructuring affects DNA probability estimates).

Contrary to its purely scientific facade, the compilation of DNA evidence is prone to various subjective forces. Determining which racial databases will be used and presented to juries, based on the probability that the suspect will be of a particular race, involves speculation and, most likely, social prejudice. See Barry C. Scheck, *DNA and Daubert*, 15 CARDOZO L. REV. 1959, 1964-66 (1994). Further, the laboratory tests themselves are not foolproof; as many as 1 in 25 "match" reports are false positives. See Jonathan J. Koehler, *Error and Exaggeration in the Presentation of DNA Evidence at Trial*, 34 JURIMETRICS J. 21, 26 (1993). Nonetheless, a recent Gallup telephone poll suggests that 77% of adults (theoretically representative of potential jurors) believe that DNA blood tests are "very reliable" or "somewhat reliable" in matching blood to an individual, and only 8% thought the tests were "somewhat" or "very unreliable." See Gallup Poll, Survey 9/18/94 to 9/20/94.

68. See, e.g., RICHARD J. HERRNSTEIN & CHARLES MURRAY, *THE BELL CURVE: INTELLIGENCE AND CLASS STRUCTURE IN AMERICAN LIFE* (1994) (discussing the provocative hypothesis on the correlation of race and intelligence).

69. See DONALD SCHÖN, *THE REFLECTIVE PRACTITIONER* (1983).

70. See PALMER, *supra* note 15, at 125-37; Larry I. Palmer, *Research with Human Subjects As a Paradigm in Teaching*, 16 LAW, MED. & HEALTH CARE 183, 183-84 (1988).

clients' position for settlement. He did not have a theory of the responsibility of individuals for the institutional arrangements in which they operated. Most significant, Gray did not consider whether his role as general counsel to the Tuskegee Institute might have blinded him to a theory of organizational responsibility for the harm to his clients.<sup>71</sup> His theory of the role of race is perhaps understandable in our post-1960s optimism, in which courts are the primary public policy makers on racial matters.<sup>72</sup>

Lawyers who were crafting settlements and drafting legislation in the aftermath of the public outrage over the Tuskegee Study might have operated without a conception of the relationship of law to the institutions of modern science and medicine.<sup>73</sup> Such an institutional conception is all the more necessary today, when modern medical research, particularly in its quest for the genetic understanding of health and disease, has heightened the ability of professionals to "play the God Game" because of patients' faith in medical progress.<sup>74</sup>

The Tuskegee Study raises questions beyond the obvious ethical impropriety of not obtaining informed consent for a study involving human subjects. That is, we need to consider whether the medical and legal professionals involved in the Study were in fact "good" individuals who were unable to see that they practiced under "bad" institutional arrangements. We must refocus on the Tuskegee Study to learn how legal encounters with human experimentation can help us to devise the best institutional arrangements between law, medicine, and modern science.

## II. THE REGULATORY MODEL

### A. *Cost-Benefit Analysis Under the National Research Act*

Another legal legacy of the Tuskegee Study is legislative. After Senate hearings on the Study, Congress passed the National Research

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71. See JONES, *supra* note 2, at 216.

72. The Supreme Court's approval of the executive branch's detention of people of Japanese ancestry during World War II might have made Gray a little less optimistic about the Court's ability to remedy the political effects of racial prejudice. See *Korematsu v. United States*, 323 U.S. 214 (1944); see also KOMESAR, *supra* note 38, at 202-03 (suggesting in his critique of the World War II race cases that courts were unable or unwilling to stop the executive branch from interning).

73. See Larry I. Palmer, *Life, Death, and Public Policy*, 81 CORNELL L. REV. 161 (1995) (reviewing KOMESAR, *supra* note 38).

74. See ROTHMAN, *supra* note 15, at 247-62 (discussing the relationship between the regulation of medical research and patient trust in physicians and hospitals); see also KATZ, *supra* note 23, at 185-91 (discussing the authoritative status and high degree of autonomy accorded to professionals in a technologically advanced society).

Act of 1974.<sup>75</sup> The Act left two clear, permanent marks on the national discourse regarding the use of human subjects. First, and most significant, the Act authorized the United States Department of Health, Education and Welfare to issue regulations governing federally funded research.<sup>76</sup> The pillar of this regulatory system was the institutional review board and its supposed capacity to supervise the giving of consent.<sup>77</sup> Under this system, the members of the institutional review board would assist the investigator in her cost-benefit analysis to determine whether the use of human subjects was appropriate.<sup>78</sup> Without this institutional assurance, federal funds for the proposed research would be denied.<sup>79</sup> Current regulations governing federally sponsored research evolved from the authority granted under the Act.<sup>80</sup>

The second feature of the Act was the establishment of the National Commission for the Protection of Human Subjects, designed to advise Congress and the executive about policies regarding the use of human subjects.<sup>81</sup> Although the Commission's mandate has expired,<sup>82</sup> similar groups have become a feature of our national political life.<sup>83</sup> "Commissioning Ethics" became a political compromise between those who sought specific legal restrictions on physicians' and scientists' use of human subjects and those who opposed such restrictions.<sup>84</sup>

### *B. Adjudication After Political Equilibrium*

Formation of a multidisciplinary group to address a crisis in human experimentation does not require congressional action.<sup>85</sup> In

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75. Pub. L. No. 93-348, 88 Stat. 342 (codified as amended at 42 U.S.C. §§ 201 to 300aaa-13 (1994)).

76. 42 U.S.C. § 212.

77. *Id.*

78. *Id.*

79. *Id.*

80. See FINAL REPORT OF THE ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS, *supra* note 20, at 108. The regulations cover research sponsored by federal agencies and research at institutions receiving federal grant support. See *id.* Thus, all university-sponsored research is covered by these regulations. See *id.* Research performed by private companies not receiving government support is not necessarily covered by the regulations. See *id.* Similarly, the regulations do not govern research conducted by United States citizens outside of the United States. See *id.*

81. 42 U.S.C. §§ 201-211.

82. See H.R. REP. NO. 102-478, at 66 (1992). The Commission was established by Congress in 1974 and went out of existence in 1978. See *id.*

83. See *id.* at 67-100.

84. See ROTHMAN, *supra* note 15, at 168-89.

85. See *id.* at 189.

January 1994, following numerous media reports of secret government experiments, President Clinton issued an executive order establishing the most recent Advisory Committee on Human Radiation.<sup>86</sup> When President Clinton announced in October 1995 that he had received the *Final Report of the Advisory Committee on Human Radiation Experiments*,<sup>87</sup> we learned officially<sup>88</sup> of other government-sponsored research involving patients and research subjects. The Committee's Report chronicled the fifty-year history of experiments on the effects of human radiation, and like previous government reports on human experiments, it recommended that the government pay the individuals who were unknowing participants in government-sponsored scientific experiments.<sup>89</sup> This payment would not be for the physical harm caused by the experiment, but rather for the "indignity" of being experimented upon without consent.<sup>90</sup> In effect, the Committee asked itself: "Should we compensate those who suffer for medical progress?" and answered the question with a resounding, if somewhat lengthy: "Yes."

I have no objection to Congress's enacting legislation to provide financial compensation to some of the subjects of government-sponsored human radiation experiments. Government compensation, however, should not be a complete bar to individual recovery. Political solutions, ultimately, are compromises in any sense, but we should recognize the imperfections of previous political solutions, such as the National Research Act of 1974.<sup>91</sup> In a separate individual statement, one member of the Radiation Advisory Committee, Jay Katz, who was also a member of the Tuskegee Syphilis Study Ad Hoc Study Panel, expressed his disappointment with the failure to develop a national policy on the use of human subjects.<sup>92</sup> Katz's doubts about the capacity of institutional review boards within research organizations to re-

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86. See Kenneth R. Feinberg, *Radiation and Responsibility*, WASH. POST, Oct. 19, 1995, at A23, available in 1995 WL 9267889.

87. FINAL REPORT OF THE ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS, *supra* note 20.

88. The information about the alleged radiation experiments had been known for some time, but there was no official government recognition of how widespread the practice might have been. *Id.* at 502-04. Congress compensated some of the individuals involved in radiation experiments sponsored by the CIA. *Id.* at 513-14.

89. *Id.* at 512.

90. *Id.* at 512-13. The Commission's Report contains recommendations ranging from issues of record keeping on human experimentation to providing Congress and the executive access to information on special actions. *Id.* at 512-40.

91. Pub. L. No. 93-348, 88 Stat. 342 (codified as amended at 42 U.S.C. §§ 201 to 300aaa-13 (1994)).

92. See Statement by Committee Member Jay Katz, FINAL REPORT OF THE ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS, *supra* note 20, at 547.

solve policy conflicts is symptomatic of a larger societal problem.<sup>93</sup> The political equilibrium<sup>94</sup> we have achieved on human experimentation is fragile and subject to disruption by public events, such as the media report of secret government radiation experiments.<sup>95</sup> Although revelations of past human experimentation may bring media attention and congressional hearings, they do not necessarily produce new legislation or court opinions that change the present structure. Legislation enacted in the aftermath of the Radiation Advisory Committee's Report should leave open the possibility of individual lawsuits.

The litigation surrounding the radiation experiments at the University of Cincinnati General Hospital warrants close attention because it tells a story about modern human subject research.<sup>96</sup> First, although it has been known for some time that radiation experiments took place for many years at Cincinnati General Hospital, until recently the identities of the patients were not known.<sup>97</sup> One might assume that the connection of these experiments to military efforts and professional notions of confidentiality may have cloaked the subjects'

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93. *See id.*

94. The phrase "political equilibrium" is borrowed from William N. Eskridge, Jr. and Philip P. Frickey. *See* WILLIAM N. ESKRIDGE, JR. & PHILIP P. FRICKEY, *CASES AND MATERIALS ON LEGISLATION: STATUTES AND THE CREATION OF PUBLIC POLICY* (1988); William N. Eskridge, Jr. & Philip P. Frickey, *Foreword: Law As Equilibrium*, 108 HARV. L. REV. 27 (1994) [hereinafter *Law As Equilibrium*].

95. *Cf.* Eskridge & Frickey, *Law As Equilibrium*, *supra* note 94 (discussing the disruption of political equilibrium by events such as war and controversial Supreme Court decisions).

96. *See In re Cincinnati Radiation Litig.*, 874 F. Supp. 796 (S.D. Ohio 1995). In these studies, which were conducted at Cincinnati's General Hospital from 1960 to 1972:

[R]esearchers from the University of Cincinnati College of Medicine exposed 87 mostly poor, African-American cancer patients to whole-body radiation with up to 300 rads for roughly an hour—the equivalent of 20,000 chest X rays and enough to cause more than half the patients to experience nausea, vomiting, abdominal pain, and mental confusion. Documents show that the study, funded in part by the Department of Defense, was designed to estimate how effective soldiers could be after an atomic bomb explosion.

Carol Pogash, *Chain Reaction*, CAL. LAW., Mar. 1995, at 48, 50-51.

At the time of publication of this Essay, the parties in the *Cincinnati Radiation Litigation* were considering a proposed settlement in the class action suit. *See* Tim Bonfield, *Holdouts Call Deal Far from Adequate*, CIN. ENQUIRER, Feb. 22, 1997, at B1, available in 1997 WL 5438066. The proposed settlement involved giving \$33,000 to \$66,000 to each family. *See id.* The children of three of the radiation experiment subjects opposed the settlement. *See id.*

97. *See In re Cincinnati Radiation*, 874 F. Supp. at 804. The complaint alleged that until a newspaper reporter revealed the names of some of the subjects in January 1994, the plaintiffs' counsel had no way of knowing whether their representatives had been subjects in radiation experiments. *See id.*



identities in a veil of secrecy. Clearly, medicine's connection with the military war efforts skewed the "ethics" of physicians.<sup>98</sup>

Second, most of these subjects were "poor," some were charity cases, and most were African American.<sup>99</sup> There is some similarity between the legal theories used by the plaintiffs in the Cincinnati lawsuit and the complaint filed after the Tuskegee Study in that they both alleged violations of constitutional rights.<sup>100</sup>

The trial judge in *In re Cincinnati Radiation Litigation*<sup>101</sup> denied the defendants' motion to dismiss the complaint.<sup>102</sup> I wonder, however, if the trial judge who refused to dismiss the complaints brought on behalf of the deceased, indigent, and mostly African-American patients might have been motivated by another feature of modern medicine—the tendency to forget its harms or its failures. Those who died from cancer twenty years ago at the University of Cincinnati Hospital,<sup>103</sup> for instance, are of little historical interest because we believe that they would have died regardless of our actions,<sup>104</sup> and because we claim to have learned lessons from our mistakes that will benefit future patients.

One wonders if society has become so accustomed to human research that it has accepted a view of medical progress grounded in notions of "cure" and "death." Given the advances of biomedical research, it is hard to imagine that there is harm and suffering that has been hidden from public view, such as in the Tuskegee and Human Radiation Studies. Perhaps individual lawsuits by actual victims are reminders that the harms of modern scientific medicine are not al-

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98. See, e.g., TRIALS OF WAR CRIMINALS BEFORE THE NUERNBERG MILITARY TRIBUNALS UNDER CONTROL COUNCIL LAW NO. 10 (1948) (demonstrating the most infamous example of this—the war crimes trial brought against Nazi doctors who conducted experiments upon concentration camp inmates against their will); see also KATZ, *supra* note 23, at 292-306 (providing excerpts from record of war crimes trials in which Nazi physicians were prosecuted for conducting medical experiments without subjects' consent). There is now growing evidence that the key expert on medical ethics for the United States "skewed" the facts about experiments on prisoners in the United States during World War II. See Jon M. Harkness, *Nuremberg and the Issue of Wartime Experiments on US Prisoners*, 276 JAMA 1672 (1996).

99. See Plaintiff's Complaint at 8, 10-11, Pollard v. United States, 384 F. Supp. 304 (M.D. Ala. 1974) (No. 4126-N).

100. See *In re Cincinnati Radiation*, 874 F. Supp. at 804. Plaintiffs alleged violations of their rights under the First and Fourteenth Amendments. See *id.* There are also differences between the cases in that *In re Cincinnati Radiation* alleged specific common law claims and claims based on federal statutes. See *id.* at 805.

101. 874 F. Supp. 796 (S.D. Ohio 1995).

102. *Id.* at 807.

103. *Id.* at 800-01.

104. See JONES, *supra* note 2, at 207 (applying this theory to the Tuskegee Study).

ways immediately visible. Sometimes the harm from powerful and otherwise beneficial drugs is intergenerational; the litigation over diethylstilbestrol (DES) is one such example.<sup>105</sup> At other times, the social context of medicine does not allow individual physicians and scientists to see individual harm, as in both the Tuskegee and Human Radiation examples.<sup>106</sup> For instance, determining whether radical surgery for certain cancers is more beneficial than the alternatives requires years of longitudinal studies.

We should explore the relevant competence of adjudicative, legislative, administrative, and market processes to deal with the problem of human experimentation.<sup>107</sup> Market forces—medicine, science, and how individuals respond to them—are the predominant forces that shape whether investigators view the risks to human subjects as worth taking.<sup>108</sup> Administrative or legislative responses to problems of human experimentation are likely to be dominated by the forces of medicine and science as illustrated by the National Research Act of 1974.<sup>109</sup> Thus, judicial decisionmaking in human experimentation should aim to shape the institutional processes of medicine and science by recognizing its own limitations. An individual lawsuit such as *In re Cincinnati Radiation* gives only a skewed distribution of the possible harms and benefits of atomic research.<sup>110</sup> The regulatory processes developed over the past twenty years to deal with human experimentation might actually have increased the amount of human experimentation, as well as the growth of new cures and greater life expectancy. There is also the concomitant growth in the possibility for individual pain and suffering. Perhaps nothing so blatantly shocking as the Tuskegee Study would happen now, but other such events

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105. See, e.g., *Brown v. Superior Court*, 751 P.2d 470 (Cal. 1988) (alleging plaintiffs suffered *in utero* injury from their mothers' use of DES); *Enright v. Eli Lilly & Co.*, 570 N.E.2d 198 (N.Y. 1991) (alleging plaintiff suffered injury as the grandchild of a woman who had used DES).

106. See generally George J. Annas, *Questioning for Grails: Duplicity, Betrayal and Self-Deception in Postmodern Medical Research*, 12 J. CONTEMP. HEALTH L. & POL'Y 297 (1996) (exploring the evolution of rationales used by physicians to justify experimentation on their patients).

107. See generally Nestor M. Davidson, *Constitutional Mass Torts: Sovereign Immunity and the Human Radiation Experiments*, 96 COLUM. L. REV. 1203 (1996) (discussing the Human Radiation Experiments as an example of a type of constitutional mass tort for which judicial abrogation of sovereign immunity is appropriate).

108. See Palmer, *supra* note 73, at 175.

109. See FINAL REPORT OF THE ADVISORY COMMITTEE ON HUMAN RADIATION EXPERIMENTS, *supra* note 20, at 543.

110. See KOMESAR, *supra* note 38, at 177-95.

are happening and will again happen.<sup>111</sup> This is why institutional analysis is so critical.

It is difficult to judge the effects of the post-Tuskegee regulatory scheme. I do not believe that the problem is seen as determining the optimal amount of human experimentation. Neither legislative nor adjudicative processes are very good at determining how much human experimentation is socially desirable, although each might offer some incentives or disincentives towards optimization. Despite the reports on human experimentation, we have not yet developed an adequate institutional analysis of human experimentation because our quest has been a search for bad professionals rather than bad institutional arrangements. The search for bad professionals is perhaps a job for the legislature, if it would ever consider imposing criminal sanctions for certain types of human experiments.<sup>112</sup> It is unlikely that criminal sanctions are going to be enacted in this country, as we are all so dependent upon physicians.<sup>113</sup> The hope is that law will create incentives for modern physicians to see themselves as institutionally embedded. Were physicians to see themselves as so embedded, their educational system would offer them opportunities to explore the ethical nexus between law, medicine, and science as they constantly revisit the challenges of modern medicine, including the effect of the changing social and economic context.<sup>114</sup>

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111. See generally Leonard W. Schroeter, *Human Experimentation, the Hanford Nuclear Site, and Judgment at Nuremberg*, 31 GONZ. L. REV. 147 (1995-1996) (discussing the development of law regarding human radiation experimentation).

112. The "crime against humanity" from the Nuremberg trial, for instance, has never been enacted into domestic law. Furthermore, in the few instances in which prosecutors have tried to use existing homicide statutes to question physicians' actions regarding patients, courts have established high barriers to criminal liability. See, e.g., *Barber v. Superior Court*, 195 Cal. Rptr. 484, 488-89 (Ct. App. 1983) (expressing the court's disappointment with the legislature's inaction to provide a proper framework for deciding ethical medical issues); see also PALMER, *supra* note 15, at 99-107 (discussing the recent unsuccessful attempts in California to prosecute criminally physicians for removing a life-support system from a critically ill patient).

113. See KATZ, *supra* note 15, at 209 (explaining the intense bonds that patients unilaterally form with their doctors).

114. See PALMER, *supra* note 15, at 42-43. Ten years ago, the hospital was the most important organizational structure for physician practice. See *id.* at 42. Most people, even members of the medical community, considered hospitals as simply places where doctors treated patients. See *id.* With greater recognition of the role of the hospital as a forum for research came safeguards against the moral risks inherent in human research. See *id.* at 43. With the advent of managed care, the social and economic structure of medicine is undergoing radical change that requires a rethinking of the traditional model of patient consent as the ethical imperative of modern practice.

## CONCLUSION

Despite being battered by revelations of secret, government-sponsored human experiments, we continue the marriage of science and medicine without examining whether, within our faith in the present paradigm, there are dangers to ourselves and our loved ones that should be faced through appropriate legal response. When confronted with abuses in the human experimentation process, legally trained individuals have asked: "Should we compensate?" As this Essay suggests, that may not be the correct question for developing marginally better social responses.

The response to the Tuskegee Syphilis Study demonstrates that the core public policy issue that Congress, courts, and institutions of higher education will have to address is the relationship between science and medicine. The questions that must be asked about the human experimentation process must be different from those posed by the Committee on Radiation and its predecessor commissions.

Regardless of whether Congress and the various federal agencies respond effectively to the Radiation Committee's recommendations, at least one lawsuit will serve as a means of portraying this tragic part of our history. Whatever damages might be awarded through adjudication or settlement, we should resist our institutional biases as legally trained persons to be satisfied with paying for human suffering.<sup>115</sup> We need thorough institutional analyses of law, medicine, and science so that law can minimize the amount of human suffering that comes in the name of medical progress.<sup>116</sup>

Lurking in the shadow of our current paradigm of paying victims for their unknowing conversion into research subjects is the idea that money should at some point overcome our moral revulsion to using individuals as instruments of progress. The idea is shameful on a number of counts and is not an ethos that we wish to leave as our legal legacy. Put in these terms, it should make us think of the real problem with the concept of paying for suffering: pain and suffering are not quantifiable and are not comparable among individuals. On what basis, then, can these victims' suffering ever be given monetary value? It might well be that paying the victims, as we continue to do, perpetuates the cycle of loving people because they are susceptible to kindness.

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115. The pain and suffering metaphor from tort law is having more influence in the physician-assisted suicide debate. Physicians have started to discuss their obligation to fight against pain just as they once argued that they should fight against death. See Palmer, *supra* note 73, at 169.

116. See KOMESAR, *supra* note 38, at 53-97.