

The Nature of Blacks' Skepticism

About Genetic Testing

Dorothy E. Roberts*

I. INTRODUCTION

Professor C. Leonard Huskins taught a genetics course at McGill University during the 1930s with Arthur Steinberg.¹ One day Huskins explained to the class why he had a keener interest in eugenics than Steinberg: "Because Dr. Steinberg is a Jew, he believes that genetics has relatively little to do with intelligence and character Because I'm an Englishman, I believe that heredity has much to do with it."² The lesson of this story is that people approach genetics from different perspectives: those in powerful positions often find solace in genetic explanations of their superiority, while those in subordinate positions are more skeptical about genetics' explanatory power.

The history of eugenics in America and Nazi Germany in the first half of this century tells us that genetic knowledge is susceptible to abuse.³ Racial minorities are particularly vulnerable to the misuse of genetic information.⁴ In a society in which Black traits are consistently devalued, a focus on genetics will more likely be used to justify limiting Black reproduction rather than encouraging it. It is not surprising, then, that black Americans might be skeptical about the value of genetic test-

* Professor, Rutgers University School of Law—Newark, New Jersey. I would like to thank Decanda Faulk for her valuable research assistance.

¹ DANIEL J. KEVLES, *IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY* 232 (1985) (reporting author's interview with Arthur Steinberg).

² *Id.*

³ See generally MARK HALLER, *Eugenics: Hereditarian Attitudes*, in *AMERICAN THOUGHT* (1984); KEVLES, *supra* note 1; ROBERT N. PROCTOR, *RACIAL HYGIENE: MEDICINE UNDER THE NAZIS* (1988).

⁴ See Patricia A. King, *The Past as Prologue: Race, Class, and Gene Discrimination*, in *GENE MAPPING: USING LAW AND ETHICS AS GUIDES* 94, 103 (George J. Annas et al. eds., 1992); see also Laurie Nsiah-Jefferson & Elaine J. Hall, *Reproductive Technology: Perspectives and Implications for Low-Income Women and Women of Color*, in *HEALING TECHNOLOGY: FEMINIST PERSPECTIVES* 93, 109 (Kathryn Strother Ratcliff et al. eds., 1989).

ing. There is a startling paucity of research on racial disparities in attitudes about genetic testing. In the absence of a careful examination, Blacks' skepticism might be confused either with ignorance about the benefits of medical information or with an irrational fear of modern technology.

In this essay, I explore the nature of Blacks' skepticism about genetic testing by reviewing studies about Blacks' health beliefs and attitudes toward various medical interventions. I contrast Blacks' views on genetic and reproductive technologies with their views on life-prolonging treatment. These studies suggest that Blacks are not opposed to medical technology *per se*, but are rightfully suspicious of the ends to which this technology will be used. In short, Blacks' problem with genetic testing does not stem primarily from ignorance about technological advances, but rather from social justice concerns. Our task is not simply to increase knowledge about genetics, but, more importantly, to ensure the just use of knowledge about genetics.

II. REPRODUCTIVE TECHNOLOGIES

One of the most striking features of advanced reproduction-assisting technologies, including in vitro fertilization (IVF), fertility therapies, and genetic testing, is that they are used almost exclusively by Whites.⁵ Only about one-third of all couples experiencing infertility seek medical treatment; and only 10% to 15% of infertile couples seeking treatment use advanced techniques such as IVF.⁶ Blacks make up a disproportionate number of infertile people *avoiding* reproductive technologies. Moreover, white women seeking treatment for fertility problems are twice as likely to use high-tech treatments as black women.⁷ Only 12.8% of black women, compared with 27.2% of white women, in the latest national survey, used specialized infertility services such as fertility drugs, artificial insemination, tubal surgery, or IVF.⁸

There is some evidence that fertility doctors and clinics deliberately steer black patients away from the various reproductive technologies. Physicians import their social views into the clinical setting and may feel

⁵ I explore this topic more fully in DOROTHY E. ROBERTS, *KILLING THE BLACK BODY: RACE, REPRODUCTION, AND THE MEANING OF LIBERTY* (forthcoming 1997); Dorothy E. Roberts, *The Genetic Tie*, 62 U. CHI. L. REV. 209, 225-39 (1995); and Dorothy E. Roberts, *Race and The New Reproduction*, 47 HASTINGS L.J. 935, 937 (1996).

⁶ U.S. Congress, Office of Tech. Assessment, *Infertility: Medical and Social Choices*, OTA-BA-358 7, 49-60 (Washington, D.C.: U.S. Government Printing Office, May 1988).

⁷ See Lynne S. Wilcox & William D. Mosher, *Use of Infertility Services in the United States*, 82 OBSTETRICS & GYNECOLOGY 122, 124 (1993).

⁸ See *id.*

that fertility treatment is inappropriate for black women who they think are unable to care for their children. As a genetic counselor confessed to anthropologist Rayna Rapp:

It is often hard for a counselor to be value free. Oh, I know I'm supposed to be value free, but when I see a welfare mother having a third baby with a man who is not gonna support her, and the fetus has sickle-cell anemia, it's hard not to steer her toward an abortion. What does she need this added problem for, I'm thinking.⁹

Patricia King similarly concludes that the racial disparity in the use of clinical genetic services may be related to physician referrals.¹⁰

In addition, cultural factors may make black couples more reluctant to use these technologies. Black people may be less likely to seek a technological fix for natural circumstances beyond their control. Infertile couples' reliance on advanced technologies reflects a confidence in medical science to solve life's predicaments.

According to Elaine Tyler May, author of *Barren in the Promised Land: Childless Americans and the Pursuit of Happiness*, America's obsession with reproduction began after World War II when "a heightened faith in science and medicine gave rise to the belief that everyone should be able to control his or her private destiny with the help of professional experts."¹¹ The contemporary white women May quotes frequently express an expectation of controlling their reproductive lives through medical intervention. One explained, "[t]here is a tremendous amount of medical help available and I feel guilty not doing everything in my power to achieve pregnancy."¹² Sociologist Arthur Greil similarly observes that the affluent, white couples he interviewed "embraced the pursuit of medical/technical solutions as the most plausible approach to dealing with the problem of infertility."¹³

Some researchers have linked the contrasting response of infertile black women to their spiritual or psychological outlook on adversity. "If infertility is one in a series of negative, seemingly irreversible events in a woman's life," sums up public health expert Elizabeth Heitman, "she may be more likely to attribute it to fate or God's will than seek to ad-

⁹ Rayna Rapp, *Moral Pioneers: Women, Men and Fetuses on a Frontier of Reproductive Technology*, quoted in Nsiah-Jefferson & Hall, *supra* note 4, at 105 (lecture).

¹⁰ See King, *supra* note 4, at 103.

¹¹ ELAINE TYLER MAY, *BARREN IN THE PROMISED LAND, CHILDLESS AMERICANS AND THE PURSUIT OF HAPPINESS* 18 (1995).

¹² *Id.* at 211 (quotation omitted).

¹³ ARTHUR L. GRIEL, *NOT YET PREGNANT: INFERTILE COUPLES IN CONTEMPORARY AMERICA* 159 (1991).

dress it in science."¹⁴ In her field study of the cultural meaning of prenatal diagnosis in New York City, Rayna Rapp also found race and class differences in women's descriptions of their amniocentesis decisions.¹⁵ Most middle-class women (who were disproportionately White) accepted amniocentesis in language that resembled the language of medicine. Poorer black women, on the other hand, "were far less likely to either accept, or be transformed by, the medical discourse of prenatal diagnosis."¹⁶ These women often explained their decision either to use or to reject amniocentesis in terms of nonmedical systems of interpreting their pregnancies, including religion, visions, and folk healing.

There may be a more "rational" explanation as well for this reluctance. Considering the history of sickle-cell screening,¹⁷ the Tuskegee syphilis experiment,¹⁸ and other medical abuses, many Blacks harbor a well-founded distrust of technological interference with their bodies and genetic material at the hands of white physicians.¹⁹ In her study of amniocentesis decisions, Rapp found that some black women responded out of anger and mistrust of the medical system. Rapp interviewed a black secretary, for example, who rejected prenatal genetic testing because the lab form included a release to use discarded amniotic fluid for experimentation.²⁰ The secretary's husband worried that the amniocentesis might make the family vulnerable to abusive medical research. Concluding, Rapp noted that, "[p]aradoxically white middle-class women are both

¹⁴ Elizabeth Heitman, *Infertility as a Public Health Problem: Why Assisted Reproductive Technologies Are Not the Answer*, 6 STAN. L. & POL'Y REV. 89, 94 (1995).

¹⁵ See Rayna Rapp, *Constructing Amniocentesis: Maternal and Medical Discourses*, in UNCERTAIN TERMS: NEGOTIATING GENDER IN AMERICAN CULTURE 33 (Faye Ginsburg & Anna Lowenhaupt Tsing eds., 1990).

¹⁶ *Id.* at 31-32.

¹⁷ During the 1970s, programs that screened Blacks for sickle cell trait led to employment and insurance discrimination against Blacks, as well as restrictions on their reproductive decision-making. See generally Mark R. Farfel & Neil A. Holtzmann, *Education, Consent and Counseling in Sickle-Cell Screening Programs: Report of a Survey*, 74 AM. J. PUB. HEALTH 373 (1984).

¹⁸ See Jeff Stryker, *Tuskegee's Long Arm Still Touches a Nerve*, N.Y. TIMES, Apr. 13, 1997, § 4, at 4 (reporting that "[so] great is the mistrust that grew out of the [Tuskegee syphilis] study that it is continuing to interfere with attempts to fight AIDS in certain black neighborhoods."). See generally JAMES H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* (1981).

¹⁹ See *supra* notes 17-18; see *infra* note 44 (citing articles on unequal access to coronary care).

²⁰ See Rayna Rapp, *Women's Responses to Prenatal Diagnosis: A Sociocultural Perspective on Diversity*, in WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 219, 224 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994). In another study, Rapp found that 50% of public clinic patients, compared to 10% of private patients, break their appointment for genetic testing. See Rapp, *supra* note 9, at 105.

better served by reproductive medicine, and also more controlled by it, than women of less privileged groups."²¹

Bioethicists Jorge Garcia and Annette Dula argue that Blacks have developed their own distinctive bioethics, born from their unequal health status, experience of medical abuse, and tradition of activist philosophy.²² As Garcia maintains, "[t]he history and types of encounters African Americans have frequently had with white Americans in various professions and institutions (governmental, corporate and educational) will influence the perspectives we are all likely to take on questions about how health care professionals and institutions ought to behave."²³ Garcia suggests, for example, that an African American perspective on bioethical matters "will be inclined to distrust the 'ethics of trust' that some physicians espouse" because of medicine's insensitivity to African American needs.²⁴

I have similarly extended the feminist critique of medicine's role in gender oppression by exploring the perspective of women of color in the context of the doctor-patient relationship.²⁵ Black women's experience of racism and sexism profoundly affects their relationship to medical practice in a way that may encourage their opposition to its oppressive aspects. "Because racism makes the oppressive use of medicine so obvious to them, women of color may be more suspicious of doctors' claims of beneficence."²⁶ By examining these women's relationship to the institution of medicine, we can "uncover the way in which the practice of medicine, particularly the doctor-patient relationship, perpetuates hierarchies of power, can highlight women's forms of resistance to medical control, and can propose a vision for transforming medical ethics and the health care system."²⁷

²¹ Rapp, *supra* note 15, at 40.

²² See Annette Dula, *Bioethics: The Need for a Dialogue with African Americans*, in "IT JUST AIN'T FAIR: THE ETHICS OF HEALTH CARE FOR AFRICAN AMERICANS" 11 (Annette Dula & Sara Goering eds., 1994); Annette Dula, *Yes, There Are African-American Perspectives on Bioethics*, in *AFRICAN-AMERICAN PERSPECTIVES ON BIOMEDICAL ETHICS* 193, 193-94 (Harley E. Flack & Edmund D. Pellegrino eds., 1992) [hereinafter *AFRICAN-AMERICAN PERSPECTIVES*]; Jorge L.A. Garcia, *African-American Perspectives, Cultural Relativism, and Normative Issues: Some Conceptual Questions*, in *AFRICAN-AMERICAN PERSPECTIVES*, *supra*, at 11.

²³ Garcia, *supra* note 22, at 31-32.

²⁴ *Id.* at 36.

²⁵ See Dorothy E. Roberts, *Reconstructing the Patient: Starting with Women of Color*, in *FEMINISM AND BIOETHICS: BEYOND REPRODUCTION* 116, 116 (Susan M. Wolf ed., 1996).

²⁶ *Id.* at 117.

²⁷ *Id.*

Seeing the importance of Black people's perspective in deliberating bioethical issues changes the task before us. It is crucial not only to increase Black people's knowledge about genetic testing, but to attend to what Black people already know about it. This knowledge, including skepticism about genetic research, should be incorporated in ethical discussions about the direction and use of technological advances.

III. END-OF-LIFE DECISIONS

Race affects medical decisions made at the end as well as those made at the beginning of life. Researchers, concerned with helping physicians to be more culturally sensitive to their patients, have studied ethnic differences in end-of-life decision-making. I examine these studies to confirm that culture influences individuals' attitudes about medical technology and to shed some light on the nature of Blacks' apparent skepticism about genetic testing.

Concerned with patient autonomy, one study explored ethnic differences in attitudes in elderly patients toward the disclosure of diagnosis and prognosis of terminal illness, as well as end-of-life decision-making.²⁸ The principle of patient autonomy asserts the rights of individuals to make informed decisions about their medical care. Under this view, patients both want to know and deserve to get medical information: "patients should be told the truth regarding their diagnosis and prognosis, as well as the risks and benefits of proposed treatments, and should be allowed to make choices based on this information."²⁹ An alternative approach holds that other values, including family integrity and physician responsibility, are as important as individual rights and have been downplayed as a result of Western cultural biases on the part of the medical and bioethics communities.

The researchers found that ethnicity was the primary factor relating to attitudes toward veracity and patient decision-making.³⁰ African Americans and European Americans maintained nearly identical fidelity to the concept of patient autonomy. For example, a high percentage of both white and black respondents believed that a patient should be told of a terminal prognosis.³¹ Most also felt that decisions about life-supporting technologies should be left to the patient. Korean Americans and Mexican Americans, conversely, were more likely to believe that only the family, and not the patient, should be told the truth about such a progn-

²⁸ See Leslie J. Blackhall et al., *Ethnicity and Attitudes Toward Patient Autonomy*, 274 JAMA 820, 820-21 (1995).

²⁹ *Id.* at 820.

³⁰ See *id.* at 823.

³¹ See *id.* at 821.

sis.³² They were also less likely to believe that the patient should make decisions about implementing life support. The researchers concluded that physicians should not assume that all patients wish to receive critical medical information; some may prefer that their families handle these life-and-death matters. For my purposes, this study helps to confirm that attitudes about medical technologies are shaped by culture and not merely by economics.³³ It also shows that Blacks are not generally averse to learning medical information. Rather the study suggests that Blacks hold as strong a commitment to the notion of patient autonomy as Whites.

Another survey of patients at a county hospital in Los Angeles similarly found important differences in the views held by members of various cultural groups toward life support.³⁴ The study replicated findings that black patients are more likely to want life-support measures to be continued. Other research, for example, found that fewer Blacks than Whites died due to the termination of dialysis.³⁵ A survey of clinical patients at the University of Miami found that more Blacks than non-Hispanic Whites wanted their doctors to use life-prolonging therapy regardless of their condition, as well as aggressive intervention such as cardiopulmonary resuscitation, intensive care unit (ICU) care, dialysis, and surgery if they were either in a persistent vegetative state or diagnosed with a terminal illness.³⁶ Blacks were the least likely, on the other hand, to want physician assistance in dying.³⁷

Dr. Jill Klessig offers the case study of a 32-year-old African American man who was admitted to the clinic with a stab wound to the heart, suffering severe brain damage after undergoing cardiac arrest.³⁸ After a month of detecting no cognitive function, the ICU team wished to issue a do-not-resuscitate order, stop antibiotic therapy, and transfer him to the general medical ward. The patient's wife threatened to sue the hospital if life-sustaining treatment was discontinued.³⁹

³² See *id.*

³³ See also P.V. Caralis et al., *The Influence of Ethnicity and Race on Attitudes toward Advance Directives, Life-Prolonging Treatments, and Euthanasia*, 4 J. CLINICAL ETHICS 155, 165 (1993) (finding that racial and ethnic differences in patient attitudes toward advanced directives persisted across socioeconomic lines).

³⁴ See Jill Klessig, *The Effect of Values and Culture on Life-Support Decisions*, 157 W.J. MED. 316, 316 (1992).

³⁵ See Friedrich K. Port et al., *Discontinuation of Dialysis Therapy as a Cause of Death*, 9 AM. J. NEPHROL. 145, 146-48 (1989).

³⁶ See Caralis et al., *supra* note 33, at 157-59.

³⁷ See *id.* at 159.

³⁸ See Klessig, *supra* note 34, at 319-20.

³⁹ See *id.* A recent lawsuit also exemplifies this situation. See Frank Bruni, *A Fight Over Baby's Dignity and Death*, N.Y. TIMES, Mar. 9, 1996, § 1, at 6. A black couple sued a Pennsylvania hospital for removing their 3-year-old daughter from life support

Dr. Klessig suggests several factors that influence Blacks' preference for continuing life-support measures.⁴⁰ First, because Blacks tend to be more devoutly religious than Whites, they may believe that a miracle will save their loved one. A relative facing a life support decision may think, "[a] physician's statement that the situation is hopeless may not be adequate: only God knows for sure."⁴¹ This hope in a miracle is enhanced by Blacks' belief in the will to survive, perhaps a result of the group's overcoming centuries of oppression.

Dr. Klessig also acknowledges the role that racism plays in Blacks' end-of-life decision-making.⁴² Blacks' decisions are influenced by their fear that doctors will attempt to terminate life support prematurely because of the patient's race. This fear may stem partly from the knowledge that black patients have less access than white patients to intensive care and specialized, high-tech medical services that may prolong life.⁴³ It is well-documented, for example, that Whites suffering from heart disease are more likely to receive life-saving coronary bypass surgery than Blacks.⁴⁴

Bioethicist Annette Dula fleshed out Blacks' concern about life-sustaining treatment in the story of an ailing, elderly black woman from the South, *The Life and Death of Miss Mildred: An Elderly Black Woman*.⁴⁵ Dula suggests that despite Miss Mildred's desire to control

equipment without the family's consent. *See id.* The girl, who suffered from glioblastoma (a tumor growing around the brain stem), could breathe only with the assistance of a ventilator. *See id.* The parents refused to sign a "do-not-resuscitate" order and protested when doctors asked to take their daughter off the ventilator. *See id.* Indeed, security guards restrained the screaming couple when the hospital unilaterally proceeded to remove the ventilator, resulting in the little girl's death. *See id.*

⁴⁰ *See* Klessig, *supra* note 34, at 320.

⁴¹ *Id.* The black couple involved in the Pennsylvania lawsuit discussed in *supra* note 39 similarly explained that their religious faith influenced their distrust of the physicians' dire predictions and their hopes that their daughter would get better for a while. *See* Bruni, *supra* note 39, at 6.

⁴² *See* Klessig, *supra* note 34, at 320.

⁴³ *See generally* Robert J. Blendon, *Access to Medical Care for Black and White Americans: A Matter of Continuing Concern*, 261 JAMA 278, 279 (1989); Jose J. Escarce et al., *Racial Differences in the Elderly's Use of Medical Procedures and Diagnostic Tests*, 83 AM. J. PUB. HEALTH 948, 948 (1993); John Yergan, *Relationship Between Patient Race and the Intensity of Hospital Services*, 25 MED. CARE 592, 592 (1987).

⁴⁴ *See* Kenneth C. Goldberg et al., *Racial and Community Factors Influencing Coronary Artery Bypass Graft Surgery Rates for All 1986 Medicare Patients*, 267 JAMA 1473, 1473 (1992) (footnotes omitted); Edward L. Hannan et al., *Interracial Access to Selected Cardiac Procedures for Patients Hospitalized with Coronary Artery Disease in New York State*, 29 MED. CARE 430, 440 (1991); Mark B. Wennecker & Arnold M. Epstein, *Racial Inequalities in the Use of Procedures for Patients with Ischemic Heart Disease in Massachusetts*, 261 JAMA 253, 253 (1989).

⁴⁵ *See* Annette Dula, *The Life and Death of Miss Mildred: An Elderly Black Woman*, 10 CLINICS IN GERIATRIC MED. 419 (1994).

the circumstances of her death, her mistrust of white doctors may make her reluctant to execute a living will. When Miss Mildred is moved from the intensive care unit, she is afraid that the doctors have "given up on her" to make room for a white patient.⁴⁶ Dula recounts an exchange between Miss Mildred and her doctor about euthanasia that illustrates the potential for miscommunication. Miss Mildred is surprised that the doctor raised the subject of euthanasia "since sometimes black folks can be might touchy about white folks trying to get rid of us."⁴⁷ She continues:

But you know what? Ever since we talked about it, look like every time I turn on the TV, somebody's talking about euthanasia, and doctors helping kill off old and sick folks. Well, I ain't seen them ask nary a elderly black on none of them TV shows and news programs what they thought about euthanasia. I believe the Lord will take me away when it's time to go. Ain't nobody going to hurry me along. You got to be careful what you tell these doctors. Even the good ones.⁴⁸

Why are Blacks likely to request high tech life-sustaining treatment for a hospitalized family member even though they tend to refrain from high-tech genetic testing and fertility services? In the former case, Blacks may rely on technological intervention even in the face of physicians' recommendations to discontinue treatment because of a distrust of doctors' appreciation of their loved one's life. In the second, they may shy away from genetic technologies out of fear that these technologies will be used to experiment on or discriminate against them. Both responses, then, are consistent with a suspicion of the medical profession born out of a history of disrespect and abuse.

IV. CONCLUSION

Understanding the source of racial differences in attitudes about medical technologies changes the research agenda in the field of genetic testing. We should be less concerned about overcoming Blacks' cultural resistance to genetic testing and more concerned about eliminating the racist practices that underlie Blacks' skepticism about genetic testing. Indeed, that cultural resistance, based largely on mistrust of the medical profession and social justice concerns, should be incorporated into ethical deliberations about genetic testing and research. Addressing Blacks' skepticism about genetic testing, then, requires more than increasing Blacks' knowledge about this technology. It requires critically assessing the uses to which the new genetic knowledge will be put.

⁴⁶ See *id.* at 426-27.

⁴⁷ *Id.* at 424.

⁴⁸ *Id.* at 424-25.