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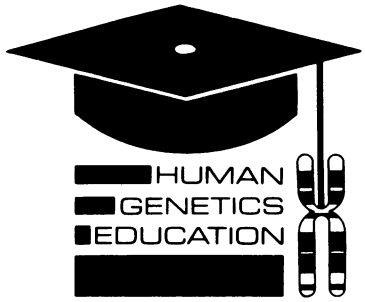
FEATURE ARTICLE
Bioethics for Human Geneticists: Models for Reasoning and Methods for Teaching



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Summary

The ethical issues raised by the Human Genome Project (HGP) and by human genetics in general are not entirely novel. In fact, the ethical issues surrounding genetic research and the provision of genetic services fit into the evolution of bioethics, a field of inquiry which has its roots in concerns of the 1970s, concerns about the dignity and self-determination of individuals and about the development of medical technologies. Although bioethics has been largely occupied with patient-centered concerns, attention is currently shifting toward socially oriented issues, such as the justice of the existing health-care system. Genetic counseling has already incorporated many of the lessons of early bioethics and, as a profession, adheres to a consultand-centered ethic which reflects the values incorporated into the doctrine of informed consent, which is a cornerstone of bioethics. The mandate of the Ethical, Legal, and Social Implications Program of the HGP—to anticipate ethical problems arising from advances in genetics and to educate the public about genetics—reflects not only the nonpaternalistic approach of early bioethics but also bioethics' increasing attention to the ethical import of systemic and institutional factors, as well as an anticipatory and preventive approach to dealing with ethical concerns. Because bioethics has so much to contribute to current consideration of ethical issues in human genetics, it is important to provide training in ethics to those working in the field. Guidelines for using a case-oriented approach are suggested.

No single article could consider all of the ethical issues related to the Human Genome Project (HGP) and to the provision of genetic services. Articles and books discussing these issues now constitute a voluminous and rapidly growing body of literature. A Department of Energy (DOE) bibliography of this literature, published in May 1992, contained over 2,600 entries (Yesley 1992*a*). By September 1992, 800 additional entries were included in the computerized-database form of the bibliography (Yesley 1992*b*).

In this paper, therefore, I merely indicate some directions in the ethical consideration of both genetic research and the provision of genetic services and place them in the context of the evolution of bioethics. First, I briefly trace this evolution. Second, I consider the ideal genetic counselor–consultand relationship as a reflection of the (patient-centered) lessons and (autonomy-oriented) values of the first stage of bioethics' evolution.

In the third section, I outline a paradigm for bioethical reasoning, modeled on principles of preventive medicine, which may prove useful now, in the second stage of bioethics, when ethical issues concerning human genetics are gaining prominence and when bioethics is turning its attention to the effect of social and institutional factors on health care and on health-care ethics (Forrow et al., in press). Finally, drawing on this paradigm for bioethical reasoning and on substantial cumulative experience teaching bioethics, I suggest how the insights and methods of bioethics might be taught to those working in human genetics.

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I. The Evolution of Bioethics

Bioethics, as an interdisciplinary field involving clinicians, lawyers, philosophers, theologians, and other humanists, was born in the early 1970s amid technological advances in medicine and growing respect for persons in society. The era was marked by the end of the Tuskegee syphilis study, the first widespread use of hemodialysis and mechanical ventilation, abortion reform, and the first human heart transplant. Technological capabilities clashed with individuals' values. In short, bioethics was born of conflict.

Respect for individuals' rights of self-determination came into conflict with some social values and with the medical profession's previously largely unchallenged paternalistic concern for patient well-being, as the medical profession and individual professionals—not patients—defined "well-being." In 1970, for example, Paul Ramsey published his patient-centered medical ethics treatise, *The Patient as Person* (Ramsey 1970). The field of bioethics emerged in the wake of landmark legal cases, such as Karen Quinlan's parents' bid to remove her from her respirator (In the Matter of Karen Quinlan 1976) or the paralyzed Mr. Canterbury's suit claiming that he had not been fully informed of the risks of his surgery (Canterbury v. Spence 1972). Bioethics evolved to provide a legal and ethical framework within which to resolve conflicts between physician and patient and between social consensus and individual values. The individual patient's values came to trump the traditional values of medicine, and the privacy both of individuals and of the physician-patient relationship erected a boundary against the intrusion of society's interests.

If the physician-patient relationship was a primary locus of this first generation of bioethics, the crisis of funding health care is emerging as the focus and fundamental challenge of bioethics in the 1990s. (Even earlier, some, notably Norman Daniels [1985, 1988], Daniel Callahan [1987], and Governor Charles Lamb, drew attention to the challenges presented by limited resources.) The focus of bioethics is shifting, in this second generation, from the locus of the individual healthcare provider and recipient to social policies and institutional contexts (Jennings 1990).

Developments in theoretical ethics—specifically growing interest in feminist ethics—support this refocusing of attention. Feminist philosophers suggest that, in order to provide just answers to ethical questions, ethics must pay increased attention to the social context of these questions and, especially, to political dynamics, balance of power, and history of oppression (Frye 1983; Friedman 1987; Sherwin 1992, pp. 49–57).

In this intellectual and social climate, in 1990 the HGP was initiated to support and coordinate efforts of the National Institutes of Health (NIH) and the DOE to produce genetic linkage and physical maps of the human chromosomes and to sequence human DNA. The Ethical, Legal, and Social Implications (ELSI) program of the HGP was charged with anticipating the social consequences of the acquisition of this knowledge and developing policies to guide its use. As part of their contribution to this joint effort to encourage research and education on the ethical, legal, and social implications of human genetics research, NIH and DOE devote, respectively, 5% and 3% of their genome budgets to ELSI program activities. The ELSI program is thus both the first federally supported extramural research initiative in ethical issues and the largest source of public funds for bioethics.

ELSI program issues are not, however, really novel. Whether and how people can be taught to act virtuously was a burning public issue at least 2,300 years ago (e.g., in Plato's *Meno*). Most would agree that these fundamental questions have yet to be satisfactorily and precisely answered. Nevertheless, despite the ELSI program's annual expenditure of approximately $5 million from the public coffer, the lack of novelty of its topics should not be disturbing. First, to those who especially fear the technology created by the HGP, the fact that the issues raised by the HGP and studied under the ELSI program are not new may be a comfort. We have been wrestling with not merely virtue and justice, but with more topical concerns, such as protection from research risks and privacy protection for some time. The issues raised by the HGP will not take either bioethics or society by surprise.

Second, it should please those who are concerned by the fact that we have been wrestling with these ethical concerns for some time and have not yet created a just society, an adequate system of health care, or foolproof safeguards of privacy and human subjects that the HGP and its ELSI program will draw both attention and resources to these concerns with the promise, if not the certainty, of progress. And, because the issues raised by the HGP are not novel, guidelines and policies which are successfully developed, for example, to manage genetic information, may serve as models for the management of nongenetic medical information.

Indeed, the portfolio of the awards already made under the ELSI program reads somewhat like a compilation of excerpts from the *Encyclopedia of Bioethics*

(Reich 1987). The topics are familiar, with an occasional twist: informed consent, justice, gender justice, privacy, confidentiality, discrimination, genetic discrimination, health-care needs, and private health insurance versus a national health service. Most of these topics are not raised uniquely by genetics. For example, even those challenges to the premises of a private health insurance system which are presented by genetic screening are also presented by other predictive medical tests, e.g., cholesterol screening for hypertension. Advances in genetics may, however, raise some of these familiar concerns on a grander scale (e.g., almost everyone may be determined to be at increased risk for developing *some* disease, and actuarial pools may thus become too fine-grained to afford risk and cost spreading). Or, new genetic technologies may cause ethical concerns to arise at a different stage of life or of decision making (e.g., prior to conception or at a presymptomatic stage of a disease).

Because the ethical issues are not, however, utterly novel, it will benefit scientists, clinicians, policymakers, and the public to examine the lessons and trends in the evolution of bioethics as they consider these issues in relation to the HGP and the application of its technologies and discoveries. I would now like to turn to two of the lessons from this evolution: models of the provider-patient relationship and the doctrine of informed consent.

II. The Character of Genetic Counseling: A Lesson Learned from Bioethics' First Generation

If the conflict between paternalism and autonomy is seen to have been played out in the context of the doctor-patient relationship since the 1970s, the genetic counselor–consultand relationship of the 1980s and 1990s seems to reflect the resolution of that conflict. Prior to the 1970s, a priestly model accurately described the typical paternalistic doctor-patient relationship. According to this model, the locus of decision making is taken from the patient and placed in the hands of the expert professional who is charged with benefiting the patient; in the extreme, the physician's "moral authority so dominates the patient that the patient's freedom and dignity are extinguished" (Veatch 1972, p. 7). In contrast, the physician-patient relationship model which is currently advocated in medical school curricula and medical literature is a contractual model, according to which ethical authority and responsibility are shared by professional and client: "The basic norms of freedom, dignity, truth-telling, promise-keeping, and justice are essential to a contractual relationship. The promise is trust and confidence even though it is recognized that there is not a full mutuality of interests. . . . With the contractual relationship there is a sharing in which the physician recognizes that the patient must maintain freedom of control over his own life and destiny when significant choices are to be made" (Veatch 1972, p. 7). The relationship between professional genetic counselors and their consultands reflects this shared decision-making process, which guarantees to consultands the authority to make choices reflecting their own values. Primary tenets of the Code of Ethics of the National Society of Genetic Counselors (NSGC) state that genetic counselors strive to "respect their clients' beliefs, cultural traditions, inclinations, circumstances, and feelings . . . [and] refer clients to other competent professionals when they are unable to support the clients" (NSGC 1992). Thus, the consultand-centered, autonomy-oriented conception of the genetic counseling relationship reflects the outcome of at least 2 decades of bioethical discussions of patients' rights, the therapeutic advantage of involving patients in their own care, and recognition of value pluralism.

The nonpaternalistic, nondirective process of genetic counseling also embodies aspects of the doctrine of informed consent, the most prominent bioethical and legal doctrine to emerge in the early years of bioethics. Informed consent is the process whereby competent patients or research subjects are informed of the risks and benefits of proposed therapeutic or research protocols ("disclosure"), are asked to weigh these risks and benefits in light of their own values and desires, and are asked to give their informed, voluntary consent to undertake the therapy or to participate in the research (Appelbaum et al. 1987). Health-care professionals and researchers are obligated to disclose the information in such a manner that a reasonable layperson can understand it and to answer the specific questions which the individual client or research subject may raise. Insofar as the professional or researcher becomes aware of a particular client's or subject's desire to have additional information disclosed, the professional or researcher incurs an obligation to make reasonable attempts to satisfy that desire ("dialogue"). The doctrine of informed consent has two justifications: first and most fundamental, respect for persons and their autonomy; and, second, protection of individuals' welfare by requiring their consent as a prerequisite to incurring the risks of research or treatment (Beauchamp and Childress 1989, pp. 74–75).

The fundamental role of genetic counselors (indeed of all medical geneticists, including gene therapists, in their counseling capacities) is to provide information to enable consultands to make free and informed reproductive and health-care decisions. The NSGC Code of Ethics states that counselors "strive to enable their clients to make informed independent decisions, free of coercion, by providing or illuminating the necessary facts and clarifying alternatives and anticipated consequences" (NSGC 1992). Supplying information in an understandable manner, answering consultands' questions, helping consultands develop the understanding necessary to make their own decisions, and supporting those choices are the primary tasks of genetic counselors. Whereas these tasks, which are included in the disclosure and dialogue stages of the process of informed consent, are just one facet of other health-care providers' jobs, they constitute, in broad outline, the primary tasks of genetic counselors.

Thus, in an important sense, the first 2 decades of bioethics not only provided background for current ethical consideration of issues arising from genetic research and from the management of genetic disease, but actually laid the foundation for the process of modern genetic counseling.

As the HGP progresses and genetic services become a more integral part of health care, ethical analysis of issues concerning these rapid advances in genetic technology and knowledge will continue to reflect this individual-oriented bioethical tradition. However, consideration of a second generation of more socially oriented bioethical concerns will coincide with and be influenced by these advances in genetics.

III. Genetics and the Challenges of Bioethics' Second Generation

Second-Generation Concerns: Social Resources, Social Structures

As the rhetoric of the 1992 Presidential election suggested, health-care costs, equity in health care, and thus health-care reform are popular issues. In bioethics anthologies, there is growing attention to "resource allocation" issues (Beauchamp and Walters 1982; Mappes and Zembaty 1991). Moreover, these issues are no longer primarily questions of microallocation or triage ("Who should receive this organ?") but instead focus on macroallocation concerns, such as how to provide a decent minimum of health care to all of society's members, what constitutes a decent minimum, and whether certain types of health care should be available at all ("Should organ transplantation research or well-baby clinics receive funding?").

Even at the microlevel of the individual patient, there is growing awareness that social values and policies and institutional structures play an important role in determining individuals' health status and health-care opportunities. Women whose health insurance packages reimburse for mammographic screening, for example, are more likely to receive mammograms according to the guidelines of the American Cancer Society (1989) than are those whose insurance companies reimburse only for mammograms ordered by a physician because of a positive finding (e.g., a lump) on physical examination.

Preventive Ethics: A Model for the Second Generation

Although bioethics in its first generation was largely concerned with the resolution of ethical conflicts—just as acute care–oriented American medicine has traditionally directed most of its resources toward health-crisis management, i.e., toward treating symptomatic illnesses (Payer 1988)—bioethics in its second generation is gradually beginning to address the social and institutional factors which may create or exacerbate ethical problems. In this way bioethics may be said to parallel what many would take to be a welcome development in American medicine—namely, preventive medicine (Fisher 1989). The practice of "preventive ethics," including its anticipatory stance and its attention to social and institutional factors, mirrors the practice of preventive medicine (Forrow et al., in press).

Early bioethics' pragmatic emphasis on resolving ethical conflicts betrays a myopia which limits its value in four ways (Forrow et al., in press). First, waiting until a conflict arises makes resolving ethical quandaries more difficult, because by then medical and institutional factors may limit options (e.g., a patient may become incompetent and unable to supply necessary information about his wishes) or opposing parties may have become deeply entrenched and personally identified with their (conflicting) positions. Second, even successfully resolved crises therefore incur high human costs, e.g., in terms of time and emotion expended in their resolution.

Third, the crisis-resolution approach measures success in terms of whether a settlement of the particular crisis can be found and thus too readily accepts patterns of recurring ethical problems. In its early years, bioethics neglected the underlying causes of ethical conflicts, such as routine aspects of health care or social and institutional structures which have exacerbated or even directly caused ethical conflicts in the provision of

health care (Barnard 1985). In particular, the values which drive nonclinical social forces (e.g., political and economic forces) differ from—and in some cases directly oppose—basic clinical-ethical, patient-centered values (Relman 1980, 1984).

Fourth, because the traditional approach defines the scope of bioethics in terms of discrete problems, it necessarily fails to attend adequately to the ethical aspects of health care in which no specific "problem" has been identified. Outside genetic counseling, for example, the disclosure and dialogue inherent in informed consent are often ignored until the physician and patient disagree about the proper treatment, even though the process of informed consent is important in defining the ethical character of every provider-patient interaction.

In contrast, a preventive approach to bioethical issues can help overcome these limitations of early crisis-oriented bioethics, in three ways. First, a preventive-ethics approach places greater emphasis on preventing the development of ethical conflicts (Pincoffs 1971). Second, a preventive-ethics approach thus emphasizes the detection of potential ethical conflicts at stages where "symptoms" of the conflicts are not yet present or are relatively mild. A preventive-ethics approach emphasizes understanding the predictable patterns of "pathophysiology" (Appelbaum and Roth 1983) and "ethical risk factors" shared by common ethical problems. By drawing attention to those factors which lead to ethical quandaries (e.g., institutional structures or different cultural or religious views), practicing preventive ethics can facilitate the development of mechanisms to avert serious conflicts or to reach ethically defensible plans more readily, thereby minimizing unnecessary personal anguish and social conflict.

Finally, preventive ethics correctly recognizes that the absence of ethical conflict is an inadequate measure of the ethical provision of health care or ethical conduct of research (Forrow et al., in press). The goal of preventing ethical conflicts is as incomplete a foundation for the field in preventive ethics as the goal of preventing disease is for the field of preventive medicine, which includes health promotion. The cardiovascular aspects of patient care, for example, are inadequately addressed by criteria of health which are fully satisfied when no discrete cardiovascular disease or risk factor is identified; the patient's cardiovascular health may still be poor. Similarly, preventive ethics not only seeks to avoid conflicts, but also strives to create and preserve relationships of trust and understanding between providers and recipients and between researchers and the public. It seeks to maximize opportunities for the exercise of autonomy and the provision of quality patient- or consultand-centered care.

According to a preventive-ethics approach, alternative social policies should be judged not merely according to whether they will prevent open ethical conflicts, but also according to their capacity to promote ethical health care and the opportunity for society's members to pursue life plans reflecting their own values. In expanding the focus of bioethics from decisions in problematic cases to a general concern with both the routine aspects of health care and the social and institutional factors which affect health care, preventive ethics more fully integrates ethical considerations into health care and research.

Preventive Ethics and the ELSI program

The mandate and current projects of the ELSI program of the HGP reflect a preventive-ethics approach. Rather than waiting for ethical conflict to erupt in the genetic counselor's or insurance agent's office, it is the mandate of the ELSI program to anticipate ethical, legal, and social problems and to craft policies to avoid them. Furthermore, there is widespread recognition that the identification and solution (or avoidance) of these ethical concerns requires examination of their context, including social and religious mores as well as political, economic, and institutional structures. The mandate of the ELSI program and the execution of its aims thus reflect both the concerns of this second generation of bioethics and a preventive approach to addressing these concerns.

The educational function of the ELSI program seeks to achieve the third goal of preventive ethics: to create and preserve relationships of trust and understanding between those working in human genetics and the public. By informing the public of advances in genetics and by seeking public comment on the use of both the technology developed and the knowledge gained, the ELSI program seeks not just to avoid social conflict over the ethical issues raised, but also to give the public an opportunity to influence the research agenda, to shape the character and promote the "ethical health" of the HGP.

Preventive Ethics and Social Policy: Insurance

Preventive ethics' emphasis on identifying recurrent problems and formulating ethics protocols for dealing with them (*i*) may avoid some individual hardship (or at least permit individuals to anticipate and prepare for future hardships), (*ii*) may, by identifying the problems, invite their innovative solution, and (*iii*) may prompt

changes in existing structures and policies, if these structures and policies are themselves contributing to the problems.

Researchers anticipating the effect of genetic testing on *life* insurers' treatment of applicants determined that, although few consumers thus far have made formal complaints to state insurance commissioners, and although the commissioners do not perceive genetic testing to represent a significant problem in life insurance underwriting, life insurers do enjoy considerable legal latitude to require genetic testing (McEwen et al. 1992). Such research, combined with the fact-gathering efforts and policy recommendations of the Task Force on Genetics and Insurance of the NIH-DOE Joint Working Group on ELSI, constitutes the first step in taking a preventive-ethics approach to concerns about the ability of those at genetically increased risk of disease to obtain health and life insurance. The next stages involve principle and policy development and implementation (Loewenson 1992).

A preventive-ethics approach would dictate that nongenetic precedents be examined: for example, individuals with certain medical profiles—HIV seropositivity or hypertension—have difficulty obtaining health insurance. By first identifying this as a recurrent, nonisolated problem, individuals may avoid hardship by seeking alternative forms of insurance, by lobbying to change the rules of their current company's policies, or even by acting on this additional incentive to avoid the risks of becoming HIV^+ or hypertensive. By identifying this problem as a recurrent one, researchers and policymakers may be prompted either to devote energy and resources to developing alternative means of funding health care for individuals with these medical profiles or to reform the existing health-insurance system (e.g., by applying to self-insuring employers the regulations of ERISA [1985], which are now imposed only on insurance companies, or by more radically reforming health care, as the current administration is proposing).

Policies successfully developed to provide health insurance to HIV^+ or hypertensive individuals may serve as model policies for those who have genetically based increased risk of disease; moreover, policies addressing the needs of HIV^+ or hypertensive individuals should, according to a preventive-ethics approach, be crafted with the needs of the much larger population of those at genetically increased risk of disease in mind. At the very least, practicing preventive ethics would suggest that actuarial treatment of asymptomatic insureds who are at genetically based increased risk of heart disease, Huntington chorea, or cancer not be handled on an ad hoc basis, after the fact of an insured's screening, but instead be set by policy made known to insureds prior to their screening.

Preventive Ethics in Genetic Counseling

Practicing preventive ethics in genetic counseling suggests, for example, that developing guidelines for disclosure of medical information to third parties may more effectively protect privacy and preserve patients' trust than would multiple individual attempts to redress breaches of confidentiality. Establishing and making known, prior to testing, a counseling center's policy on disclosure of nonpaternity and other incidental findings may avoid conflict and facilitate establishment of a trusting, collaborative relationship between counselor and consultand (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983). Some policies may be most appropriately set and promulgated at a counseling center–wide level. Other issues may invite professional society guidelines (e.g., guidelines concerning preservation of consultand confidentiality) or governmental regulation (e.g., quality assurance of laboratories doing DNA screening for forensic purposes).

Justice demands that like cases be treated alike. New policies and individual actions must therefore either be consistent with existing social policies or force those policies to be amended. A preventive-ethics approach emphasizes that examination and (adequately promulgated) amendment of existing policies, practices, and institutions are fair game in determining how to resolve current questions ethically. Practicing preventive ethics and acting justly with respect to demands for genetic testing for purposes of fetal sex selection would, for example, require either that any social policy concerning sex selection be consistent with other social policies or that existing policies be amended. Thus one might require either (*a*) that any proposed federal policy prohibiting abortion on the basis of genetic information concerning fetal sex be consistent with current policy permitting first-trimester through mid-second-trimester abortion without any statement of reasons for the abortion or (*b*) that existing policy on abortion must itself be reexamined (Fletcher 1979). Anyone attempting to establish a federal policy which instead focused on the genetic testing itself and sought to prohibit testing to determine fetal sex should bear in mind recent experience with the so-called gag rule, which attempted to regulate what physicians in federally funded clinics could advise their patients about abortion (Department of Health and Human Services, Public Health Service 1988;

Rust v. Sullivan 1991). Ultimately, this governmental regulation of the private interaction of health-care providers (or at least physicians) was thought to interfere with the privacy of physician-patient interactions, to violate protection of freedom of speech and standards of care, and to leave physicians open to charges of malpractice (Annas 1991), and the gag rule was struck down. For similar reasons, a policy prohibiting genetic testing to determine fetal sex for sex selection should probably not be imposed by bodies outside the genetic counseling profession. Such a policy should be established, if at all, by the medical professions themselves, e.g., by the NSGC, as part of its Code of Ethics.

Like feminist ethical theory, a preventive-ethics approach recognizes that while, in theory, people may be equal, rational beings, they are differently situated in the social and economic power structures of society. Therefore, practicing preventive ethics requires taking into account the likely different effects of policies on people of different social, economic, and educational backgrounds. A preventive-ethics approach to establishing a fetal sex-selection policy would therefore demand that the policy be crafted so that it would not unfairly prevent only the uneducated or medically unsophisticated from receiving fetal sex-determination services, while permitting the sophisticated (i.e., those who know enough to lie about their reason for seeking testing) to achieve their ostensibly socially undesirable aim.

Preventive Ethics in Genetic Research

In genetic research, practicing preventive ethics might require that, at the start of their studies, family-studies researchers establish policies concerning disclosure of interim results or the number of times they will telephone a recalcitrant family member to remind him to return his blood sample or questionnaire (so as not to unduly pressure him to continue in the study by calling too frequently). Practicing preventive ethics may require that a researcher not promise that a blood sample will be used to answer only one study question, unless he can ensure that, with the single question answered, the sample will be destroyed and that, without the sample, no additional information can be extrapolated from the original study (because it is probably the information, not the sample itself, which the subject wishes to control). Experience suggests that careful composition of institutional review boards (IRBs), complemented by the drafting and promulgation of guidelines for research, may protect research subjects more effectively than would multiple individual attempts to redress breaches of confidentiality or to regain the trust of a population which feels ill used.

The creation of the NIH's Recombinant DNA Advisory Committee (RAC), for example, represents an attempt to anticipate and address ethical concerns pertaining to gene therapy. Because RAC provides a safeguard against employment of potentially high-risk gene therapy in the absence of safety and efficacy data, a recent decision to exempt one therapeutic protocol on a compassionate-plea basis raises concern (Thompson 1992, 1993). By responding to the crisis of the moment and not fully addressing the precedent-setting ramifications of its departure from its peer-review protocol, the NIH's departure from its preventive-ethics stance both invites concerns about the susceptibility of its peer-review process to political pressure and constitutes a potentially serious breach of public trust.

Preventive Ethics, the HGP, and the Past

In drawing attention to recurrent ethical problems, preventive ethics, like several strains in feminist ethics, suggests the importance of attending to history, particularly the history of the allocation of power. Especially in considering the eugenic and discriminatory potential of genetic knowledge and technologies, preventive ethics demands that we be mindful of eugenic policies of the mid-twentieth century and of America's past and current fascination with using forced sterilization to decrease the incidence of such "medical conditions" as feeblemindedness and pauperism or such social ills as welfare motherhood (Procter 1988; Reilly 1991). What is sex or racial discrimination, after all, but discrimination based on genetic differences?

Writing 20 years after the Tuskegee syphilis study was stopped, Harold Edgar, a law professor who represented some of the study subjects in litigation, observed that "no such program could possibly have continued so long but for the central fact that participants were African Americans" (Edgar 1992, p. 34). (In the study in the rural South, approximately 400 poor, illiterate black men suffering from syphilis were observed in order to chart the course of untreated syphilis. The study began in 1932 and was ended, after an exposé in the *Washington Star,* in 1972. The men were kept in the study by a variety of inducements, such as free medical treatment for other conditions, and deception. In the 1940s, when penicillin became the drug of choice for the treatment of syphilis, the men were prevented from receiving it.)

Of group differences, Edgar observes that "the horrors of the Holocaust and the pervasive racism that

still afflicts American life make it impossible for many people even to contemplate that different groups may be different in lots of ways. . . . [And yet,] the Human Genome Project will bring to the forefront of human consciousness awareness of the range of variability not only among individuals but among groups. To acknowledge those differences, while insisting on their irrelevance to respect for individual dignity and equality of right, is a challenge we shall have to face" (Edgar 1992, p. 35).

Study of the ethical import of past research projects and treatment of genetic differences throughout history provides background for current discussion of the ethical conduct of research and management of genetic disease. The cultural, economic, political, and religious forces which influenced policy development, research conduct, and health-care provision may become more clear in retrospect. Hindsight may yield a set of markers which signal possible ethical impropriety; we must teach ourselves to be acutely aware of these ethical markers as we take an anticipatory, preventive-ethics stance.

Teaching Ethics in the Context of Human Genetics

There is thus great demand for ethics teaching in the context of human genetics. The optimum curriculum for genetic counselor–training programs calls for the inclusion of "social, ethical, and legal issues in genetic counseling" (Scott et al. 1988, p. 192). A 1988–89 study of British medical schools by the Royal College of Physicians revealed that 91.2% of the 202 medical school professors and the 38 nonmedical school faculty who responded felt that the ability to "perceive major ethical issues in medical genetics" was a valuable or obligatory genetic skill (Harris 1990, p. 750). A 1989 report of the Information and Education Committee of The American Society of Human Genetics on the teaching of human genetics in medical schools noted that "appreciation of ethical dilemmas . . . demands not only a thorough understanding of the impact of disease on the individual, family, and society but a sensitivity of what this implies within those spheres" (Charman and Graham 1989, p. 605).

The question is how best to impart ethics education to the researchers, genetic counselors, and medical geneticists who confront myriad ethical questions in their daily work in human genetics. The goals, timing and context, and method of such educational efforts must be considered.

Modifying the goals of clinical ethics training (Forrow et al. 1991), I propose the following as four primary goals of ethical training relating to human genetics. Researchers and clinical geneticists (e.g., physicians and genetic counselors) should learn to:

1. identify ethical issues arising in the context of their daily work and recognize the hidden value assumptions and unacknowledged conflicts among these values which accompany these ethical issues (e.g., cultural, personal, and religious values or legacies of historical events);
2. think critically about these issues in ways which lead to ethically justifiable courses of action and articulate the reasons constituting that ethical justification;
3. implement the ethically justifiable courses of action;
4. identify occasions when determining the ethically justifiable course of action requires consultation with others, including institutional and regulatory bodies with additional expertise or authority, (e.g., university or hospital counsel or the IRB).

An ethics curriculum should therefore create awareness of the ethics resources available to those who must wrestle with ethical issues, including human resources (e.g., ethics consultants or committees, or IRBs) and published resources (e.g., governmental and institutional guidelines and the vast literature of bioethics). Genetic counselors, in particular, may find the non-genetics-related bioethics literature of special interest, because they frequently find themselves supporting consultands during difficult medical ethical decisions not directly related to genetics, e.g., the withdrawal of hydration and nutritional support from a seriously impaired newborn.

Ideally, ethics education should be incorporated into all aspects of researchers' and clinicians' training (Baird 1989). One of the most comprehensive and still-evolving curricula in medical school uses a case-oriented approach throughout the preclinical and clinical years of medical school and residency training (Frader et al. 1989). A case-oriented approach which sparks lively discussion, from which theoretical ethical points may emerge, is typically favored (Clouser 1980). Before the students have clinical contact, richly detailed hypothetical cases, which are realistic albeit not real, are used to generate discussion in relatively small groups (Clouser 1989). Once students are involved in clinical care themselves, they are asked to present a case from their own experience to a still smaller discussion group of approximately 6–12 students. Bench scientists may be similarly

trained in ethics. In their early years, hypothetical cases may be used for discussion (Poynter Center 1991); later, these scientists should be asked to reflect on their own research and that of their colleagues to raise ethical questions for discussion.

Although instructors, who are drawn from a variety of disciplines (e.g., medicine, nursing, philosophy, law, and history), differ in their discussion-leading approaches, students generally are asked to conduct what is termed an "ethical workup" (Thomasma 1978). Amended to encompass consideration of issues arising in the genetic research context and to accommodate a preventive-ethics approach, the steps of an ethical workup would include:

1. identification of significant medical and scientific factors and their likely consequences;
2. identification of human factors concerning the parties involved (e.g., the consultand or research subjects, their families, clinicians or researchers, taxpayers, or future generations);
3. identification of significant social, political, economic, religious, and professional and personal value factors present for those parties involved in the case, including any relevant policies, guidelines, and law;
4. identification of conflicts among these value factors (often by means of identification of conflicting parties) and identification of opportunities to promote ethical values;
5. establishment of priorities among the conflicting values or development of policies which permit preservation of the conflicting values;
6. articulation of the criteria used to establish priorities, including ethical norms.

The first step—identification of medical and scientific facts—may prompt historical reflection on what has counted as "scientific fact" (e.g., the genetic basis of pauperism) and invites students to develop a healthy skepticism about the objectivity of science. The second step encourages students to recognize not only who will be affected by an action, but also who stands to benefit from particular resolutions of the ethical question and who, therefore, might exert inappropriate influence in the ethical decision-making process.

The third step—identification of relevant normative factors—invites consideration of the relationship between so-called medical or scientific facts and value-laden assumptions. Students may be prompted to consider whether more complex social explanations may, in fact, be more accurate than the supposedly scientific one. (The popular press, e.g., reports that children of parents who suffer from seasonal affective disorder [SAD] are themselves more likely to experience SAD and jumps to the "scientific" conclusion that this suggests a genetic basis for SAD.) In this third stage, students extrapolate from the medical and scientific facts and human factors to the values of the parties involved. In keeping with a preventive-ethics model, students are asked to identify which policies or structures might be amended to avoid future similar conflicts, as well as to identify the influence of past allocation of power, cultural differences, and various value commitments.

In the fourth and fifth steps, students practicing preventive ethics are asked not only to identify conflicting ethical values, but also to identify opportunities to promote ethical values, e.g., by instituting policies to encourage study participants to ask questions (thereby promoting their autonomy) or by keeping records of consultands' experiences of genetic discrimination to supply in congressional testimony or to lobby the insurance industry (thereby promoting social justice). By identifying the nature of the values conflict or opportunity for values promotion (e.g., truth telling versus welfare promotion, or the chance to enhance self-determination), students are (i) prompted to identify the intimate relationship between ethical questions and medical or scientific questions, (ii) taught the vocabulary which enables them to have access to bioethics literature published on the topic, and (iii) prompted to recognize similarities among cases of a similar nature.

A preventive-ethics approach in step five would attempt to preserve both conflicting values—at least in future cases of a similar nature—by designing new (or by altering existing) policies respectful of both values. A genetic counseling center, for example, might establish and promulgate a policy stating that nonpaternity will be specifically disclosed only to mothers but that the accurately assessed risk of having a future affected child will be disclosed to both partners planning to conceive. The solidarity of the couple (welfare) may thereby be promoted while the importance of disclosing information truthfully to the party to whom it will be both useful and least damaging is respected.

In the last stage it is useful to identify similarities between the reasons given or criteria used for priority setting and the tenets of various ethical theories. Noticing those similarities may lead to a more rich critique of the justifying reasons offered in a particular case. If, for example, priority has been given to achieving a good outcome (e.g., the alleviation of a newborn's suffering), identification of the reason for the decision as a conse-

quentialist one facilitates examination of the reason from other perspectives (e.g., a rights-based perspective which warns that seeking only to promote desirable outcomes can lead one to ignore the rights of others). In the final stage, ethical theory, as well as the cumulative experience of bioethics, may be brought to bear on the particular problem and its future prevention.

Conclusion

I have tried to suggest how clinicians and researchers in human genetics may benefit from the evolution, literature, and methods of the American bioethics movement. The genetic counselor–consultand relationship reflects the outcome of early bioethical discussions. The mandated preventive-ethics approach of the ELSI program reflects the goal of a second generation of bioethical concerns focusing on society's health-care responsibilities and on the effect of biotechnology on both individuals and social institutions. As was the case with the evolution of clinical ethics, the integration of bioethics education into the training of genetics researchers and clinicians should have a beneficial effect on the relationship between these professionals and the public they serve and on the acceptance and efficacy of new genetic technology.

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