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Legal Aspects of Genetic Information

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The federally funded Human Genome Initiative will lead to the development of new capabilities to learn about an individual's genetic status. Legal issues are raised concerning patients' and other parties' access to that information. This article discusses the effect of existing statutes and case law on three pivotal questions: To what sort of information are people entitled? What control should people have over their genetic information? Do people have a right to refuse genetic information? The article emphasizes that the law protects a patient's right to obtain or refuse genetic information about oneself, as well as the right to control the dissemination of that information to others.

The fruits of the Human Genome Initiative—on which over a billion dollars will be spent in the next 15 years to map and sequence the human genome—will help to push us from the old genetics to the new genetics [1]. Under the old genetics, predictions about genetic disease were made based on an individual's family history or on diagnostic tests which measured gene products, such as proteins. Disorders were treated, for the most part, after symptoms appeared. For many genetic diseases, there was no treatment—so couples were faced with the agonizing decision of whether to abort an affected fetus.

Under the new genetics, direct diagnosis will be made of the genes themselves. The clinician will gain information about an individual's genetic predispositions to certain diseases (such as lung cancer) or the fact that the individual will suffer from a late-onset disorder such as Huntington's disease. New treatment may also be developed using genetic technologies. In September 1990, for example, the National Institutes of Health approved the first proposal to use gene therapy in humans [2]. The protocol involves gene therapy in children with severe combined immune deficiency, caused by the lack of the enzyme adenosine deaminase (ADA).

The Human Genome Initiative raises not only medical challenges but legal ones as well. In fact, 3 percent of the budget for the Human Genome Initiative will be devoted to research not on the scientific, but on the *ethical* ramifications of mapping and sequencing the human genome [3].

The key ethical and legal issues that have been identified thus far revolve around the use of genetic information [4]. The first is: *To what sort of genetic information are people entitled?* For example, are people entitled to the results of a test that has not yet been perfected and so gives ambiguous results? Should they be told about which environmental stimuli to avoid when they have a genetic predisposition to harm from those stimuli? Should they be told of the new significance of previously rendered genetic tests?

The second issue is: *What control should people have over their genetic information?*

Abbreviations: ADA: adenosine deaminase DES: diethylstilbestrol PKU: phenylketonuria

For example, should people be able to prevent disclosure of their genetic status to relatives, insurers, employers, or law enforcement officials?

The third issue is: *Do people have a right to refuse genetic information about themselves?* Could the government, for example, force adults to acquire genetic information about themselves through mandatory screening programs?

THE SCOPE OF DISCLOSURE

As genetic technologies grow more sophisticated, the medical community is increasingly able to discover deleterious genes in individuals, which indicate that they are carriers of genetic disorders or that they already have or will develop genetically based diseases or handicaps. Much of such predictive capability has been in the reproductive field, enabling parents to discover in advance whether they might be passing on to their offspring a handicapping or fatal genetic illness. These developments have led to concomitant legal responsibilities. Health care professionals must warn individuals of the genetic risks they and their potential offspring face, must disclose the availability of testing to diagnose genetic status, and, if such testing is requested, must perform it in an acceptable manner [5]. If they do not, they face the possibility of a wrongful birth case [6] brought by the couple or—in a handful of states—a wrongful life case [7] brought by the child.

But the new diagnostic tests being developed are not as clear-cut as the tests for Down's syndrome or Tay-Sachs disease that served as the basis for the previous lawsuits. As a result, questions arise about the scope of disclosure required—for example, with respect to ambiguous results or genetic predispositions.

The Case of Cystic Fibrosis

The case of cystic fibrosis illustrates the issue of ambiguous results. In August 1989, the gene for cystic fibrosis was identified [8]. Three months later, the American Society for Human Genetics called for a voluntary moratorium on widespread population screening, and a National Institute of Health conference quickly followed suit. There is a concern about the need to establish mechanisms for education and counseling, and a worry about the manpower resources needed to do so. Since one in 25 Caucasians in the U.S. is a carrier, up to eight million people would be identified by the test [8], and there are not enough genetically trained health care providers to meet that new responsibility. Another reason for caution is the fact that the test identifies only about 70 percent of cystic fibrosis carriers who have not yet had an affected child. This fact means that "[f]or every couple who could be helped by the test, there will be about 25 more in limbo, in which just one is a carrier" [8]. Pediatrician Michael Kaback has called for pilot programs "to evaluate, among other things, which educational approaches work best, how many people elect to be tested, just what the counseling needs are, and 'how much fear we create' " [8].

Could a couple who gives birth to a child affected with cystic fibrosis sue the obstetrician or genetic counselor for not revealing that a cystic fibrosis test is available? Such a suit might be brought, but it seems unlikely that the couple would prevail, given the current high likelihood that the couple would receive ambiguous information. Once the test increases in its predictive value, though, such suits would be permissible, even given the manpower shortage in the genetics field.

Part of what will determine whether health care providers are held liable for disclosing or not disclosing the availability of the cystic fibrosis test will be the

standards that the health care providers themselves set. And it seems that geneticists tend to put a high value on disclosure. Dorothy Wertz and John Fletcher surveyed 677 geneticists in 12 countries (including the United States) [9]. In response to a hypothetical case involving a disagreement with colleagues about ambiguous laboratory results of prenatal diagnosis, 97 percent said they would disclose the disagreement. Such a finding suggests that geneticists might impose upon themselves the duty to inform about the availability of the cystic fibrosis tests long before the courts impose it upon them.

Genetic Services in Non-Reproductive Settings

The legal cases regarding negligence in genetic counseling and testing have generally involved negligence with respect to genetic services in connection with people's reproductive decisions. Genetic testing can, however, be used to identify genetic defects that indicate, not a risk for the patient's offspring, but a risk for the patient himself or herself [10]. The test may show that the patient will suffer from a late-onset disorder [11] or that the patient is at risk of developing a particular disease when exposed to environmental stimuli [12]. Failure to advise of the existence of such tests or negligence in performing them could lead to malpractice actions against health care professionals. In addition, there is a potential for malpractice liability for not informing the patient about lifestyle changes that could lessen the chances of a genetic disorder expressing itself.

New channels of genetic research promise to uncover more genetic defects that result in diseases only when combined with a certain environmental stimulus. Already, some physicians are advising parents of children with a genetic propensity toward skin cancer to move to an area with a rainy climate [13]. As this type of research progresses, health care providers may be liable for not warning patients about those aspects of the environment (diet, job, climate) that could trigger a disease.

This duty will touch more health care professionals as genetic research expands from an emphasis on birth defects to an emphasis on chronic disease. Research on identifying genetic propensities to coronary artery disease or diabetes, for example, will make genetic concerns relevant to every area of medical practice.

Analyses of medical school curricula show that the teaching of genetics is not emphasized. Practicing physicians have an inadequate grasp of genetics [14]. The existence of a duty to disclose the genetic basis of disease may require changes in medical education to assure that physicians in all areas of practice have a greater awareness of genetics.

Duty to Re-Contact Patients

As new scientific information linking certain gene types to particular diseases is uncovered, the health care provider may have a responsibility for re-contacting patients and former patients who may now be known to be at risk (conceptually, a "genetic recall") or who would benefit from new tests or treatment possibilities. The current rapid evolution of genetic diagnostic testing, and the possible relation of established tests to new tests, makes it likely that the existing information a physician has about a patient will subsequently take on new meaning. For example, a physician may use a diagnostic test on a patient to learn the level of a certain gene product, such as an enzyme. At the time the test is employed, the physician may be aware that

a high level of the product indicates carrier status for a serious autosomal recessive disorder. The physician may provide the test for hundreds of patients, duly noting the results in the record, and informing those patients with a high level that they are carriers and that, if they mate with another carrier, they have a 25 percent chance of giving birth to an affected child.

By following such a protocol, the physician will have admirably discharged his or her current responsibility. But what happens when later (a month, a year, a decade), it is learned that a low level of the gene product signals carrier status for a different, although equally fatal, disorder? The physician now has information in the files about other individuals who might give birth to a child with a fatal disorder. Does he or she have a duty to contact those individuals and disclose that fact? Existing case law precedents about such things as the Dalkon Shield [15] and diethylstilbestrol (DES) [16] held that the physicians had a duty to re-contact patients to disclose previously unknown risks of a treatment [17]. These precedents could be extended to find a duty to disclose this situation as well.

Similar situations may arise with respect to other types of genetic diagnostic techniques. Certain tests have been used to determine if a person was a carrier of a particular autosomal recessive disorder. The traditional learning was that a carrier was not herself at health risk, but that, if she mated with another carrier, she might give birth to an affected child. In recent years, however, research has indicated that carriers of single gene recessive disorders might have a predisposition toward developing other types of health problems. For example, carriers of homocystinuria apparently are at higher-than-average risk for developing cardiovascular disease. Again, physicians and genetic counselors might thus be responsible for re-contacting patients and former patients who had been identified as carriers in order to advise them of this newly discovered health risk.

Yet another problem situation exists when an infant is diagnosed and treated for a genetic disorder, but subsequently reaches reproductive age without realizing that he or she has been affected by a genetic disease. In the 1960s, state public health departments began screening infants for metabolic disorders, such as the autosomal recessive disorder, phenylketonuria (PKU) [18]. Upon discovering positive test results, the state notified the affected children's doctors so that treatment could begin on the affected children. The PKU children were put on a special diet to prevent mental retardation, but many stopped the diet before age seven. As female children enter their childbearing years, they may not remember that they had been diagnosed as having PKU or that they had been fed the special diet. Some are beginning to have children of their own, without realizing that there is a high likelihood that they will give birth to a mentally retarded child if they do not go on the diet during pregnancy [19]. Efforts are already under way to re-contact PKU girls when they reach age 13 to advise them of the effect of the disease before they become pregnant.

Each of these scenarios raises questions of the duties of health care professionals to patients and former patients. If the individual is still a patient of the professional, it is reasonable to expect the professional to disclose the new (or the now relevant) information. That responsibility seems more attenuated when the individual is no longer a patient. The practitioner might claim that there should be no duty to re-contact a former patient in these situations since physicians do not have a duty to re-contact patients with other types of disorders when new information is available to

aid their condition. For example, physicians are not thought to have a responsibility to contact a former cardiac patient when a new diagnostic test or treatment technology becomes available; however, the genetic scenarios are distinguishable. The issue is not whether the physician has a duty to advise a patient of a potential new service. Rather, the issue is whether the practitioner has a duty to advise the patient of the new implications of a previously rendered service (i.e., the diagnostic test which has new significance). There are no direct legal precedents for this situation; courts are likely to apply the logic of cases creating duties to disclose subsequently discovered risks of treatment.

CONFIDENTIALITY

The second major issue concerns confidentiality and the type of control people should have over their genetic information. Medical records containing genetic information are particularly volatile. Unlike an infectious disease, a genetic disorder is generally immutable. Thus, an inappropriate disclosure may haunt the individual throughout his or her life. The revelation of genetic information can cause serious financial, emotional, and perhaps even physical harm to the patient. An employer might decide to fire an employee based on the evidence that the employee, later in life, would suffer from a late-onset disorder. An insurance company might decide not to provide coverage of that person, based on the same information.

Courts now recognize causes of action against health care providers and health care institutions for breaches of confidentiality on several grounds: breach of contract [20], violation of privacy [20,21], malpractice [22], and breach of fiduciary duty [20,22]. They could also recognize a cause of action based on interference with contractual relations or infliction of emotional distress. Indeed, as one court pointed out, "[t]he promise of secrecy is as much an express warranty [on the part of the health care provider] as the advertisement of a commercial entrepreneur" [23].

A physician may in certain instances breach confidentiality in order to protect third parties from harm. For health care professionals, this possibility came up vividly in the early part of the century as a duty to warn members of a patient's family when the patient was suffering from an infectious disease [24,25,26], such as smallpox or typhoid. Subsequently, psychiatrists were found be have a duty to warn intended victims of their potentially violent patients [27].

How would the law address the issue of disclosure of genetic information? As with the cystic fibrosis example, part of the answer to that question will depend on the standards geneticists and other health care providers set for themselves. In a survey of 295 geneticists in the United States, Dorothy Wertz and John Fletcher found that most would not breach confidentiality and report to employers or insurers without the patient's permission. Only 12 percent of the geneticists said that they would provide the information to insurers without consent and 24 percent would disclose information to employers without consent [9].

This attitude is in marked contrast to the geneticists' feelings about disclosure to relatives. Wertz and Fletcher questioned the geneticists about whether they would contact relatives against the wishes of a patient who had a defective gene for Huntington's disease or hemophilia A. They expected that more would breach confidentiality and warn relatives who were at risk for hemophilia A, since it is treatable, while Huntington's disease is not. They found, however, that 54 percent would breach confidentiality with respect to hemophilia A and that 53 percent—

almost the same number—would breach confidentiality with respect to Huntington's disease [9]. Thus, over half the geneticists who responded to the Wertz and Fletcher survey seem to sense that their relationships with their counselees and patients give rise to a duty to warn relatives.

Disclosure to Relatives

In considering whether a health care provider should contact a blood relative over the patient's refusal, however, various factors should be weighed that do not seem to have figured in the responses to the survey, such as the likelihood that the relative has the genetic defect, the seriousness of the defect to the health of the relative and his or her children, and the likelihood that the relative's defect would be otherwise detected. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research recommended that disclosure should be made only if reasonable attempts to elicit voluntary disclosure are unsuccessful, there is a high probability of serious (for example, irreversible or fatal) harm to an identifiable third party, there is reason to believe that disclosure of the information will prevent harm, and the disclosure is limited to the information necessary for diagnosis or treatment of the third party [28]. If a genetic disorder is not serious, if it is likely that the relative's disorder will be diagnosed even if no disclosure is made, if early disclosure would not markedly change the prognosis (for example, if there were no known treatments), or if the possibility of the disorder is of relatively common knowledge (such as sickle-cell anemia among blacks or Tay-Sachs disease among Ashkenazie Jews), the need for disclosure is muted. The strongest case for disclosure of genetic information exists when the disclosure would prevent serious imminent harm to a third party.

No courts have held that there is a duty to warn relatives of patients that they, too, may be at risk of genetic disorders. Some health care professionals, however, would like to take on that responsibility.

Health care professionals in favor of contacting relatives who are at risk should be aware of the public policy implications of their actions. Even when an individual instance presents a particularly compelling case for disclosure, health care professionals should analyze the systemic effects of undertaking disclosure. Since the duty to disclose to relatives will be measured in part by the standard of care in the medical genetics community, exercising a right to disclose may ultimately set a standard creating a duty to disclose. The ramifications of such a duty could be awesome. Consider the burdens of tracking down all the close relatives in an instance of genetic disease. Moreover, since research is increasingly revealing that many common disorders have a genetic basis, physicians in general practice or in specialties other than genetics might also be held to have a duty to inform relatives. For example, if a young man has coronary artery disease, there might be a duty to warn his siblings that they, too, may be at risk. And consider the burdens on the state public health department if, every time it found an infant who tested positive for phenylketonuria, it had a duty to contact the infant's aunts and uncles to tell them that their own children may similarly be at risk.

If practitioners begin to disclose such information to relatives, they may establish a standard of care within the profession whereby relatives who have not been contacted will sue them. Considering, in one clinician's estimate, that there are an average of three at-risk family members for each patient, and that family members

may be scattered around the country, the burdens of identifying and tracking down relatives may be great.

As a legal policy, it would seem less appropriate to require health care practitioners to disclose a patient's genetic defect to a relative than to disclose a patient's infectious disease or violent tendencies. In the latter case, the patient could potentially harm the relative. In the former case, that of genetic defect, the patient will not cause harm to the relative. The only potential argument that the health care professional could make for contacting the relative, is that, through diagnosis of the patient, the health care professional has reason to believe that the relative is at higher risk than the general population of being affected by a genetic disorder. The practitioner has, however, similar knowledge about a variety of third parties (such as the risk that pregnant women over 40 will give birth to a child with a chromosomal defect).

If the practitioner has a duty to tell a relative with whom he or she is not in a professional relationship about the enhanced risk to that relative, it would seem that a practitioner should also have an obligation to tell any other stranger about an enhanced risk that stranger faces. Such a duty would seem to be excessive, and thus it might be an appropriate policy to limit practitioners' disclosure duties to the patient alone (unless the patient will actually cause harm). Even if disclosure to relatives were undertaken, it would be of limited value and could not replace other methods of screening for or diagnosing genetic disorders. In one study of Tay-Sachs disease, the majority (82 percent) of the incidents of the disease were initial occurrences within the kindred [29].

The patient does have an ethical duty to inform relatives, however, and health care professionals should give patients help in fulfilling that duty. Genetics workers should clearly tell patients what information will be valuable to relatives. It might aid patients in contacting relatives if the clinic provided materials that could be sent to relatives. Written materials not only help the patient better understand his or her disorder or defect; they also can be duplicated and sent to relatives.

Disclosure to Law Enforcement Officials

An attempt to breach confidentiality might also be undertaken for law enforcement purposes [30]. Police may wish to obtain a blood sample from a person to see if the DNA matches that of blood, semen, hair, or other tissues left at a crime site. The Fourth Amendment to the U.S. Constitution protects people from unreasonable searches and seizures; it would not permit the wholesale blood sampling described in Joseph Wambaugh's *The Blooding.* Instead, in the United States, the police would have to show probable cause that a particular individual was linked to a crime before taking a sample of his or her blood [31].

What about the situation in which many people have banked their DNA in a clinic as part of their own medical care or for family linkage studies, and law enforcement officials want access to everyone's DNA in order to try to identify the perpetrator of a crime? If the *physical* invasion of the blood sampling is the main focus of the protection against unreasonable searches and seizures, then law enforcement officials could argue that they have a right to test without probable cause DNA that has already been banked, since there will be no additional physical invasion to the accused or to his or her property. It can be argued, however, that it is not the invasion of the accused's body or of property, but the invasion of his expectation of privacy

that is central to the accused's rights. Along those lines, the U.S. Supreme Court has held that the fourth amendment protects people in situations in which they have a reasonable expectation of privacy [32]. In that case, use of an electronic recording device on a telephone booth was held to constitute a search and seizure within the meaning of the fourth amendment, even though it had not *physically* penetrated the booth, and even though the booth was not the accused person's property. With respect to genetic information, there is similarly an expectation of privacy when a patient seeks health care. The patient does not expect the physician to disclose his or her findings.

Currently, law enforcement officials do compare fingerprints found at the scene of the crime to existing fingerprint data bases. The policy implications in the use of fingerprints are, however, radically different from those inherent in the use of DNA. Fingerprints are not collected in the course of health care. Allowing law enforcement officials to use DNA from clinical settings might discourage some people from seeking health care in the first place—a possibility that does not exist with respect to fingerprints. In addition, DNA reveals information that fingerprints do not—information about physical or mental disorders that the individual does or will suffer from. Such information—not necessary to law enforcement purposes—can cause harm to the individual if it is disclosed.

There may be limits to an argument based on the expectation of privacy, however. Statutes violating that expectation of confidentiality have been passed—for example, to require physicians to report gunshot wounds. Similar statutes might be passed to allow law enforcement officials access to banked DNA in situations in which there is probable cause. If such access—or similar access to information, rather than to the samples themselves—is a possibility, people should be informed about that possibility before they give their consent to provide DNA to the bank in the first place.

MANDATORY TESTING

The third issue raised as we move into the new genetics is whether a person should be required to learn about his or her genotype. Along those lines, Margery Shaw has already advocated mandatory genetic screening of potential parents and mandatory prenatal screening [33]. Another potential governmental role is in mandatory screening of children, which is already in effect in those states which require that infants be tested for certain metabolic disorders [34].

Case law establishes that a competent adult generally has a right to refuse medical care except in limited circumstances—primarily when the person has or is likely to develop a contagious disease that would directly harm others. Even with respect to situations in which the state has been recognized to have the power to mandate treatment, the state has been incredibly circumspect in using that power. Vaccinations have been required [35], but the government generally has not undertaken activities to track down people who might have infections and to keep them from participating in social life or force them to be treated. In the current AIDS epidemic, people have generally not been required to be tested against their will.

Although people may put themselves at risk in decisions regarding medical services, the state has been allowed to intervene when the person had a contagious disease that put others at risk due to the possibility of contagion. Some commentators argue that mandatory screening of adults for genetic disorders is justifiable under contagious disease precedents, to prevent people from "transmitting" disease

to their offspring. Margery Shaw, a physician and attorney, even goes so far as to recommend mandatory abortion to prevent the birth of affected children [33]. Under the analogy of genetic disease to infectious disease, the government could order interventions on all individuals of reproductive age (since all people carry genetic defects).

Yet such an approach interferes with couples' constitutional rights of privacy to make reproductive decisions. In April 1990, a federal judge explicitly held that the right to privacy specifically covers decisions concerning prenatal genetic testing [36]. Consequently, if a law infringes upon couples' reproductive decision-making rights with respect to the use of genetic services, the law will be upheld as constitutional only if it is necessary to further a compelling state interest in the least restrictive manner possible.

With respect to other fundamental rights, such as freedoms of speech, the government has only been allowed to interfere to protect against a danger that is substantial, imminent, and irreparable [5]. Arguably, that is the sort of danger that the U.S. Supreme Court envisioned when it upheld an emergency mandatory vaccination law [37] at a time when infectious disease presented a substantial threat to the community.

Certain infectious diseases potentially put the society as a whole at immediate risk since the diseases can be transmitted to a large number of people in a short time. The potential victims are existing human beings who may be total strangers to the affected individual. In contrast to infectious disease, the transmission of genetic diseases does not present an immediate threat to society. While infectious disease can cause rapid devastation to a community, the transmission of genetic disease to offspring does not have an immediate detrimental effect, but rather creates a potential risk for a future generation in society. U.S. Supreme Court cases dealing with fundamental rights have held that harm in the future is not as compelling a state interest as immediate harm [5].

Additionally, the policy concerns raised by attempts to stop the transmission of genetic diseases differ from those addressed to infectious diseases because genetic diseases differentially affect people of different races. Some commentators contest the applicability of the infectious disease model to government actions regarding genetic disorders because "[u]nlike infectious disease which knows no ethnic, racial, or gender boundaries, genetic disease is the result of heredity" leaving open the possibility for discriminatory governmental actions [38].

Most reasonable people would be horrified at the thought of forcing people to be sterilized or to undergo abortions against their will for eugenic reasons. Upon first consideration, however, they may not be as troubled by mandatory screening for genetic disorders in the absence of forced sterilization or abortion. Some may even argue that mandatory screening is not an infringement on procreative rights because it represents at most a modest physical invasion (for example, a blood test), and it merely provides information which the person can use in making decisions about reproduction.

The provision of information is not a value-free act, however. People have a right to waive information—for example, they can decide to waive the presentation of health care information before they consent to treatment [39]. In addition, the U.S. Supreme Court has recognized that the presentation of information in the context of reproductive decisions can coerce an individual to make a particular decision. Laws

that required that women be given information that tended to pressure them not to have an abortion have been struck down as unconstitutional. In *City of Akron v. Akron Center for Reproductive Health,* for example, the U.S. Supreme Court struck down statutory provisions that required physicians to give speculative information such as the characteristics of the fetus, including ability to feel pain, and provisions that required physicians to present "a 'parade of horribles' intended to suggest that abortion is a particularly dangerous procedure" [40].

In a 1986 case, the U.S. Supreme Court held that the required disclosure even of information that was medically accurate and objective could be unconstitutional because it tended to influence a person's reproductive decision [41]. The Court said that "[t]he States are not free, under the guise of protecting maternal health or potential life, to intimidate women into continuing pregnancies." The Court recognized that certain information—no matter how objective and accurate—is not always relevant to a person's reproductive decision, and "it may only serve to confuse and punish her and to heighten her anxiety," which is contrary to proper medical care sensitive to the individual patient's needs.

Moreover, in order to reach potential parents, screening of adolescents in school, people of reproductive age generally, or people applying for marriage licenses has been suggested; however, such screening measures carry psychological and social risks. In a Montreal Tay-Sachs screening program, several thousand people under age 18 were screened. The adolescents screened experienced anxiety when they learned they were carriers [42]. In another study, an American adolescent reportedly suffered a psychotic reaction when she was told she was a carrier of Tay-Sachs [43].

Screening of adults, too, can lead to psychological trauma. Some people have committed suicide when they learned they were carriers of Huntington's disease. In fact, deaths due to suicide are four times as prevalent among Huntington's disease patients than among the corresponding U.S. Caucasian population [44].

In addition to presenting a psychological risk to those individuals who learn that they are carriers of genetic disorders, screening can present a psychological risk to those who find they are not carrying the defective gene. According to Nancy Wexler, when at-risk individuals learn that they are not carriers of Huntington's disease, "[m]any may suffer 'survivor guilt,' particularly characteristic of wartime soldiers who live while their buddies are killed" [45].

To a limited extent, government screening of adult carriers has already begun. In Illinois, for example, the mandatory premarital medical examination is required to include sickle-cell screening if the examining physician determines it to be necessary [46]. An Alaska law requires that before a marriage license is issued, a physician certify that "the applicant has been tested, as prescribed in the regulations of the department, for the presence of infectious or heritable disease . . . " [47].

It is ironic that compulsory premarital genetic screening is being advocated at a time when compulsory venereal disease screening is being repealed. For example, New York abolished its requirements for premarital gonorrhea and syphilis testing. One of the reasons for the abolition of the requirements was that they were not the most appropriate way to reach the population at risk. The New York City Department of Health found that, in 1983, marriage applicants spent approximately $15,988,800 on premarital screening, yet this testing detected only 32 early syphilis cases. Thus, the estimated cost per case detected was $499,500 [5].

A National Academy of Sciences Committee has taken the position that genetic

screening should be voluntary [48]. This stand comports with the individual's right of self-determination. An individual may not wish to know his carrier status. Indeed, a third of the people at risk from Huntington's disease said they would not want to be tested [45]. Mandatory screening has also been criticized because it could lead to stigmatization of carriers. For example, discrimination against people at risk for Huntington's disease has already occurred [45]. If a definitive test were made compulsory, it might be used by employers or insurers to disadvantage asymptomatic carriers. Even with respect to disorders in which carrier status leads to little or no ill effects on health (such as sickle-cell anemia), discrimination has resulted in the past [5].

CONCLUSION

As a specialty within medicine, the new genetics raises certain legal issues regarding research, diagnosis, and treatment that are common to other health care endeavors. But the application of existing medicolegal principles to medical genetics does not always result in an adequate fit, for medical genetics is unique in some of the challenges it raises for individuals and for society.

Many of the legal questions raised by genetics can be handled by turning to precedents covering other types of medical practice. Nevertheless, the social, psychological, and ethical effect of medical genetics extends far beyond that of other areas of medicine. As Alexander Capron points out, "a technology that might peer into our genes and even transform them cuts to a deeper level of psychological significance than do others in biomedicine, however technically spectacular they may be" [49].

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