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GENETIC TESTING IN THE WORKPLACE: Ethical, Legal, and Social Implications

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■ **Abstract** With the completion of the Human Genome Project, it is likely that genetic testing for susceptibility to a wide range of diseases will increase in society. One venue for such increased testing is likely to be the workplace as employers attempt to protect workers from unhealthy gene-environment interactions, improve productivity, and control escalating health care costs. Past and recent examples of genetic testing in the workplace raise serious concerns that such testing could pose a significant threat to workers' privacy, autonomy, and dignity. Thus, defining the ethically, legally, and socially appropriate and inappropriate uses of genetic testing in the workplace presents a major challenge for occupational health professionals in the years ahead.

INTRODUCTION

On February 9, 2001, the Equal Employment Opportunity Commission filed suit in federal district court in Sioux City, Iowa, challenging the genetic testing program of the Burlington Northern Railway Company as a violation of the Americans with Disabilities Act (ADA). The Commission asked the court to order the railroad to end its policy of requiring all union members who claim work-related carpal tunnel syndrome to provide blood samples for DNA analysis for a genetic marker that may be related to some forms of carpal tunnel syndrome. The court papers alleged that employees were asked for blood samples but were not told the sample's purpose was genetic testing and that at least one individual who refused to provide a sample because he suspected it would be used for genetic testing was threatened with discharge if he did not submit. In the face of a legal challenge, Burlington Northern agreed to halt genetic testing of its employees (29, 51).

The Burlington Northern case is only the most recent example of the contested use of genetic testing in the workplace, but it will likely not be the last. Now that the Human Genome Project is complete, it can be anticipated that the application of new genetic information and technologies that have emerged from this project

will greatly expand in society in general and in the workplace, raising significant ethical, legal, and social issues (10). The use of emerging genetic information and technologies in the workplace has the potential to benefit worker health and safety, but their misapplication could equally work to the detriment of employees in many different ways. As is true with all applications of genetics, the current challenge in the workplace is to realize the potential benefits for workers in a manner that is ethically, legally, and socially acceptable and that minimizes the potential risks.

The roots of these issues in genetic testing are many and complex. It has been recognized for some time that the phenotypic expression of disease represents an interaction between an individual's genetic makeup and various factors in the environment, including the work environment, to which the individual is exposed over his/her lifetime (9). The contributions of genotype and environment to the phenotypic expression will vary depending on the particular disease state. The more common human diseases, such as coronary artery disease and cancer, are believed to reflect the interaction of multiple genes with a significant environmental component. In some cases, the genetic component of these complex but common disorders represents an inherited susceptibility to the development of the disease, which may emerge only in interaction with necessary environmental factors. In other cases (cancer, for example), part of the genetic component is contributed by somatic genetic changes acquired after birth, usually owing to environmental factors, including those in the workplace; these genetic alterations indicate acquired susceptibility (as opposed to inherited susceptibility) to these disorders. Of course, in all these cases it is important to recognize that the particular genetic alterations usually only indicate susceptibility for disease, not the certainty of disease, and the degree of certainty (or, in other words, the predictive value of testing for the genetic alterations) varies widely. Even in the case of the less common, single-gene inherited disorders, where we have the most experience with genetic testing and often more certainty in the test results' predictive value for revealing disease development, many different ethical, legal, and social issues have arisen (24). By mapping and sequencing the entire human genome through the Human Genome Project, which will allow the detection of genetic alterations for more single-gene disorders as well as for inherited and acquired genetic susceptibility for common disorders, these issues will undoubtedly expand.

Although it is hoped that the ability to determine the genetic component of many diseases will ultimately lead to better treatment and prevention, effective curative or prophylactic interventions have generally lagged behind detection ability. The identification of the genetic basis for disease may have value for individuals with disease or with a carrier status or susceptibility for disease. For example, with appropriate counseling, individuals who wish to know their genetic status can use the knowledge to make significant life decisions such as whether or not to reproduce. However, also important is to realize the grave potential for misuse of the ability to detect the genetic components of disease or susceptibility, both in the application of the technology and in the handling of the resulting information. The growth of the biotechnology industry increases the probability that with little

forethought and few precautions experimental scientific advances will be rapidly translated into easily accessible, commercial genetic tests. We have already seen heated debate over the availability of testing for the breast cancer susceptibility gene *BRCA1*, which some believe was offered prematurely and resulted in more harm than good (57). Inappropriate genetic testing can threaten individual autonomy, privacy, and confidentiality and lead to various types of genetic stigmatization and discrimination without any commensurate benefit for the individual tested.

As the Burlington Northern case illustrates, one venue where genetic testing is already being subject to such misuse is the workplace. Employers may have several reasons for interest in the genetic information of current or prospective employees (48, 32). First, as already noted, disease expression represents the interaction between genotype and environmental exposures, including those in the workplace. In order to minimize the potential health effects of adverse workplace exposures, employers could have an interest in identifying individuals who have a particular genetic susceptibility to such interactions to avoid placing them in jobs that might put them at risk from those exposures. The expansion in genetic knowledge will allow increasing ability to detect such genetic susceptibilities to particular exposures. In addition, since many employers subsidize the health insurance of employees either indirectly or directly (in the case of some large companies that self-insure), employers have a financial interest in the health status of employees and thus in their risk for the development of disease. The financial incentives for employers in this area are further compounded by the fact that the health of employees is increasingly found to be a major contributor to worker productivity. Together these factors contribute to the expansion of health screening and health risk assessment programs for employees, particularly with the escalation of health care costs over the past years and the recent economic downturn, which has served to emphasize the need for increased worker productivity. As noted above, the expansion of genetic knowledge will allow increasing ability to detect inherited and acquired genetic alterations that increase the risk of development of the more common diseases, greatly enhancing the power of such health screening and risk assessment. Thus, misuse of genetic testing in the employment setting could have direct adverse impacts on an individual's insurability and employability, as well as their privacy and confidentiality, personal autonomy, stigmatization, and quality of life.

BACKGROUND OF THE PROBLEM

Although the recent advances in genetics will certainly greatly expand its potential applications in the workplace, concern over the use and misuse of genetic information in the employment setting has a long history. Since the early writings about occupational disease by Paracelsus, Agricola, and Ramazzini in the 1500s and 1600s, it has been known that people who have particular workplace exposures develop much higher rates of certain diseases than the rest of the population, and that even within the same worker groups, certain individuals seemed more

susceptible to disease than others (23). For example, Ramazzini suggested that it was "not improbable that some morbid constitution proved to be more injurious" in certain cases (43). The possibility that such a "morbid constitution" might have a genetic basis and that genetic testing might be useful in identifying susceptible individuals in the workplace was first explicitly posited by the British geneticist J.B.S. Haldane in his book *Heredity and Politics*. Haldane noted:

> The majority of potters do not die of bronchitis. It is quite possible that if we really understood the causation of this disease we should find out that only a fraction of potters are of a constitution which renders them liable to it. If so, we could eliminate potters' bronchitis by regulating entrants into the potters' industry who are congenitally disposed to it. (19)

In Haldane's time, physicians had little way, other than perhaps family history, gender, or some other phenotypic marker of susceptibility, to determine if a worker might be of such a constitution. For example, at one point, some tar and creosote makers denied employment to fair-skinned workers, using skin color as a phenotypic marker for a certain genetic composition, because they thought such individuals would be more susceptible to skin cancer in conjunction with exposure to the known carcinogens in coal tar (23). However, in the intervening years since Haldane's observation, scientific advances in the ability to test various aspects of genetic susceptibility have led to increasingly more sophisticated ways to try to implement his suggestion.

Based on observations of acute hemolytic anemia among military personnel in Korea who received the antimalarial primaquine and were also heterozygous for glucose-6-phosphate dehydrogenase (G6PD) deficiency, beginning in the 1960s it was hypothesized that workers who were similarly G6PD deficient might also develop anemia under oxidant stresses from a variety of chemical exposures such as aromatic nitro and amino compounds, metal hydrides, and dyes (55). In 1963, Herbert Stokinger and John Mountain were among the first to propose the use of genetic testing for G6PD deficiency to eliminate susceptible individuals from work with such chemicals. Echoing Haldane's suggestion of 25 years earlier, Stokinger & Mountain noted with regard to G6PD deficiency:

> Most important, the determination affords, for the first time, an opportunity to make a susceptibility evaluation during the job placement examination, and, thus, avoids placing a worker in exposures to which he is inordinately susceptible. This is preventive toxicology in the highest form; no previous single development in toxicology has opened such prospects for the medical supervision of workers. Moreover, the development has added importance of not being confined solely to hemolyzing chemicals; it is envisioned as a forerunner of numerous such tests delineating other types of genetically based or environmentally imposed deficiencies. (53)

By 1973, various other genetic conditions were identified for potential workplace screening including: alpha-1-antitrypsin deficiency, sickle cell trait, and

sensitivity to carbon disulfide and organic isocyanates (54, 11). Applications in the workplace soon followed. In 1978, DuPont reported using preemployment blood testing of African Americans on a routine basis for sickle cell trait and restricting individuals who tested positive for the trait and who had low hemoglobin levels from work with nitro and amino compounds (44). Similarly, in the 1970s, the Air Force excluded African Americans with sickle cell trait from Academy admission and flight training because of presumed risk in hypoxic atmospheres (35). At the same time, over a ten-year period, the Dow Chemical Company engaged in experimental studies of cytogenetic abnormalities, using them as genetic markers of acquired susceptibility for presumed future risk of cancer and reproductive problems among workers exposed to benzene and epichlorohydrin, although the information was not used in making employment decisions (52); as noted below, these studies at Dow have recently led to a new twist to the ethical, legal, and social implications of workplace genetic testing. Over the years, other examples of genetic testing in the workplace have been noted, including N-acetylation ability, paraoxonase activity, nicotine-adenine dinucleotide dehydrogenase deficiency, and various cytochrome P450 variants, and new possibilities continue to emerge. For example, it has become possible recently to test for an inherited variation in HLA-DPB1 that may contribute to susceptibility to the development of berylliosis in some workers exposed to beryllium; however, the predictive value of the test is weak as up to 30% of unaffected individuals also carry this variant (15).

However, it has really been the Burlington Northern case that has brought the controversy over genetic testing back into the spotlight. As noted above in relation to this case, it is now possible to test for an inherited genetic predisposition to carpal tunnel syndrome (CTS): hereditary neuropathy with liability to pressure palsies (HNPP), a demyelinating neuropathy caused by deletion of the peripheral myelin protein-22 (*PMP-22*) gene. Although up to 90% of HNPP cases develop carpal tunnel syndrome, HNPP is not common, affecting only 1 in 2500–5000 individuals, and thus contributes negligibly to the incidence of carpal tunnel sundrome, making detection of *PMP-22* deletion a very inefficient way to screen for carpal tunnel genetic susceptibility (8). Besides failing to meet the minimal scientific basis for a testing program, the program failed minimal ethical, legal, and social standards in neglecting informed consent, failing to provide genetic counseling, and threatening employees with dismissal for failure to comply.

On the other hand, in some instances employees may come to expect that employers will perform genetic tests for their protection from workplace hazards, arguably making the employer legally liable if it fails to conduct appropriate genetic testing (31). In fact, Dow Chemical Company has recently been sued by the widow of a deceased employee for failure to include the employee in the aforementioned cytogenetic testing program, which might have detected early biological indications of his development of leukemia from his workplace exposure to benzene (34). The plaintiff's argument is strengthened by several studies that have demonstrated predictive value of certain cytogenetic changes for the

subsequent development of cancer (18). Although the Dow program predated these results, the case raises the concern that employers, motivated by fears of legal liability, may well be encouraged to do genetic testing in cases in which the utility for workers' health has not been well established. It also underlines the critical importance that testing can have for workers' health in appropriate cases.

Another recent lawsuit, which did not involve genetic testing, may nevertheless also have bearing on the likelihood of companies pursuing genetic testing in the future. In this case, an individual sued Chevron Oil Company because they denied him employment on the basis of his asymptomatic chronic active hepatitis C infection, which, in combination with the hepatotoxic chemical exposures in the coke oven job for which he had applied, was felt to pose a threat to his health. The Supreme Court, in interpreting the ADA job qualification standard that "an individual shall not pose a direct threat to the health and safety of other individuals in the workplace," allowed Chevron's proposed extension of this to include the worker himself (30). On this basis, one could make a parallel argument for similar situations involving genetic tests that indicate a susceptibility for disease in combination with certain workplace exposures allowing employers to deny susceptible individuals work in jobs with those exposures because it would represent a threat to their health.

EXTENT OF THE PROBLEM

Over the years, a number of attempts have been made to determine how widespread and serious the issues of genetic testing in the workplace are. The first systematic evaluation of genetic testing in the workplace in this country was undertaken in 1982 when the former Congressional Office of Technology Assessment (OTA) mailed a confidential questionnaire to the chief executive officers of the nation's top 500 companies and 50 largest private utilities, and to the presidents of 11 major unions for these companies, asking about their current, past, and anticipated future use of genetic testing. The questionnaire mailing was followed up with telephone interviews of nonrespondents, which resulted in a 65.2% response rate. Among the 366 respondents, 17 companies (5%; 8 in the chemical industry, 1 utility, and 8 others) indicated that they had used genetic testing in the workplace in the preceding 12 years, and 6 companies (2%; 2 in the chemical industry, 2 utilities, and 2 others) reported that they were then using such testing. An additional 59 companies (18%; 11 in the chemical industry, 4 in the petroleum industry, 3 in the pharmaceutical industry, 9 utilities, and 32 others) indicated that they planned to initiate some form of genetic testing of workers in the next 5 years. Among those respondents who were currently or had previously done genetic testing, 12 reported testing for sickle cell trait, 5 for G6PD deficiency, 5 for alpha-1-antitrypsin deficiency, 2 for NADH hydrogenase deficiency, 3 for liver enzymes, and 5 for immune markers. The reported scientific basis for the selection of particular tests included high

predictive value or expert consensus (39). Particularly intriguing in light of the Dow experience noted above is that three respondents noted that their rationale for testing was based on potential legal consequences of failing to test. The most commonly targeted subgroups for testing were defined by ethnicity. No respondents admitted using the results of the testing as the basis for employee dismissal, although 25 respondents did acknowledge taking actions based on the results; 8 informed the employees of the results, 5 transferred employees to other positions, 2 suggested employees seek other employment, 3 recommended use of personal protective equipment, 2 instituted engineering controls, 1 pursued additional research, and 1 discontinued the product in question. The study had some limitations including: failure to distinguish between testing for inherited genetic susceptibilities and acquired genetic damage; failure to determine the frequency and setting of testing (preemployment, routine medical evaluation, specific monitoring program, etc.); and failure to determine who within each organization actually answered the questions (e.g., medical or technical personnel versus administrative personnel) so that the probability of accurate responses was difficult to gauge (15). However, the results did demonstrate that, by 1982, genetic testing was being done in the workplace and that there might be reasons for concern about its inappropriate use. Then Representative Al Gore, who was Chair of the House Subcommittee on Investigations and Oversight of the Committee on Science and Technology, which had requested the study, noted that such genetic testing had "potential to serve as a marvelous tool to protect the health of workers or a terrible vehicle for invidious discrimination"(52).

At the time, many people believed that genetic testing in the workplace would be widely used within the next five years. In 1989, the OTA followed up with a second study in which the chief health and personnel officers of 1500 large U.S. companies, the 50 largest utilities, and the 33 largest unions were surveyed. Among the 260 respondents, 12 (5%; 4 in the chemical industry, 1 in the petroleum industry, 2 others in the manufacturing sector, and 5 others in the nonmanufacturing sector) reported that they were employing genetic testing at that time, and an additional 8 reported having done so in the preceding 19 years. Although these numbers were lower than had been anticipated, they indicated continued interest in and use of genetic testing in the workplace. For example, 2% of companies with more than 1000 employees said that they anticipated mandatory use of genetic tests by 1994, whereas another 3% said they anticipated conducting some form of genetic testing on a voluntary basis by 1994. Half of the company health officers considered the practice to be generally acceptable with 62% saying it should be the employer's decision whether and when to perform such tests (40). Another survey done at the same time by Northwestern National Life Insurance Corporation of 400 firms found that "15% of the companies reported that by the year 2000 they planned to check the genetic status of prospective workers and their dependents before making employment offers" (16).

As interest in using genetic testing in the workplace began to increase in the late 1980s and early 1990s, so did concern over its potential misuse and the

corresponding ethical, legal, and social implications. A survey in 1992 of professionals working in genetics-related fields collected 41 specific cases of genetic discrimination in the previous 2 years, all but two of which involved insurance or employment. Several of the examples from this survey clearly demonstrated that the genetic information obtained was interpreted incorrectly or applied inappropriately (6). In 1993, the National Academy of Sciences Institute of Medicine (IOM) Committee on Assessing Genetic Risks expressed concern that American workers were losing their jobs or their health insurance on the basis of information obtained through genetic testing (24). Noting that there would be commercial pressure to adopt such tests as soon as they became available, Dr. Arno Motulsky, professor of genetics at the University of Washington and chair of the IOM committee, observed that with the advent of the Human Genome Project, the use of such testing would likely skyrocket (22). By 1996, based on survey data from Geller et al. (12), the Council for Responsible Genetics had identified over 200 cases of genetic discrimination (41). Another survey based on telephone interviews of 332 volunteers from genetic support groups in 1996 found 13% had been denied or terminated from a job based on genetic information, and 17% had failed to reveal genetic information to employers for fear of job loss; 87% did not want employers to know genetic test results that would indicate high risk for the development of a disease (28).

However, despite these concerns, use of genetic testing by employers continued. A 1999 survey of corporate executives conducted by the American Management Association revealed that among 1054 responding companies, 16.7% reported using genetic testing to determine susceptibility to workplace hazards (12.8% for job applicant testing and 12.0% for employee testing), and 10.3% reported using the test results in making employment decisions (6.7% used them for making hiring decisions, 7.3% for assigning or reassigning employees to jobs, and 1.7% to determine retention or dismissal of employees). Testing for specific diseases was also reported for sickle cell anemia (0.9% of respondents with 0.2% reporting using the test results in making employment decisions) and breast or colon cancer (4.3% of respondents with 0.8% reporting using the test results in making employment decisions) (50).

As noted above, the use of genetic testing in the workplace and the resulting problems can be expected to grow. First, the now-completed Human Genome Project and related biotechnological advances will greatly increase the number and availability of genetic tests. Second, many companies are expanding efforts in general health screening as a way to minimize escalating economic costs of employee health care and to maximize economic benefits of health-related productivity, and there is every expectation that genetic testing will be incorporated into such programs in the future. In fact, the importance of the issue was recently underscored by an article labeling genetic testing in the employment setting as one of the critical business issues in the workplace for the first decade of the twenty-first century (46). The Burlington Northern case provides a timely exclamation point to this statement.

RESPONSES TO THE PROBLEM

Apart from the implications for employability and insurability discussed above, genetic testing in the workplace, as elsewhere, can have adverse effects on an individual's privacy and confidentiality, personal autonomy, and quality of life. It can also lead to stigmatization of individuals and groups (47). Therefore, as concerns over all these issues with genetic testing in the workplace have proliferated, attempts to minimize the adverse effects related to the application of the tests and the use of the information generated have increased as well.

As early as the 1970s, governmental regulatory attention was directed at the question of the use of genetic information in the workplace with regard to exposure standards of the Occupational Safety and Health Administration (OSHA). OSHA's 14 carcinogen standards of 1974 required a preassignment physician's evaluation that would include genetic factors (36). By 1980, this reference to genetic information had raised so much concern that OSHA had to clarify that there was no requirement for genetic testing of employees under the standard for the exclusion of qualified workers from their jobs on the basis of genetic testing. Then Assistant Secretary of Labor for OSHA Eula Bingham noted:

> Exclusion of workers as a result of genetic testing runs contrary to the spirit and intent of the Occupational Safety and Health Act of 1970. It wrongly puts the burden of controlling toxic substances on the worker who is denied employment because of a supposed sensitivity. Employers should make the workplace safe for all workers, rather than deprive some workers of their livelihood in the name of safety. (37)

In subsequent standard-setting processes, e.g., for ethylene oxide, OSHA again considered the possibility of including a suggestion for genetic testing, but, in the end, this was dropped (38). Therefore, the default position for OSHA apparently remains that outlined by Dr. Bingham above. However, the decision in the Chevron case previously discussed may be interpreted in the future to mean that employers can use genetic testing to remove certain at-risk individuals from workplaces and thus "deprive some workers of their livelihood in the name of safety."

Concerns over misuse of genetic testing have prompted several states to pass laws that affect its use in various contexts, including in insurance and employment settings. For example, 28 states have enacted laws that prohibit insurer's use of genetic information in pricing, issuing, or structuring health insurance (20). As many as 18 states have enacted laws prohibiting, to varying extents, genetic discrimination in employment. Some states (Florida, Louisiana) prohibit discrimination against the unaffected carriers of recessive disorders; others (Arizona, California, Connecticut, Deleware, Iowa, New Hampshire, New Mexico, New York, Oklahoma, Oregon, Rhode Island, Texas, Vermont, Wisconsin) more generally prohibit employers from performing genetic tests on applicants or employees or conditioning employment on the results of a genetic test; one state (New Jersey) comprehensively prohibits discrimination based on genetic test results or refusal

to take a genetic test or on genetic information generally (48). In addition, in 2002, Washington state amended its health privacy law to add genetic information to the definition of protected health information (25).

Existing federal legislation such as the ADA may also affect the permissible uses of genetic information in the employment setting and elsewhere, particularly in light of the Equal Employment Opportunity Commission's guideline, which states that the ADA protects individuals from discrimination on the "basis of genetic information" (45). However, as noted above, the recent Supreme Court decision in the Chevron case, though not directly addressing genetic testing, raises some question as to how this guideline would fare against an employer's intent to prevent an employee from posing a threat to his own health. The Health Insurance Portability and Accountability Act provides specific prohibitions against the use of genetic information in determining eligibility for health insurance but does not prohibit premium increases or lifetime caps on benefits that might render the guarantee of eligibility for coverage effectively meaningless (47). In February 2000, then President Clinton issued an executive order forbidding the federal government from using genetic information in employment decisions, but this order only affects the 2.8 million federal employees (26). Every year, legislation to address this issue has been introduced into Congress, but as yet, no comprehensive federal protections have been passed. Thus, the legal status of the issues can only be described as variable, scattered, and unclear.

Legal remedies to address these issues have been bolstered by ethical recommendations by private and professional organizations. For example, the Genetic Alliance, a national coalition of genetic support groups, issued a policy statement on Genetic Discrimination and Employment that proposes "basic principles. . .central to public dialogue about genetic nondiscrimination and employment" including that "access to health care, education and employment is essential to all individuals, regardless of genetic inheritance" (13). Among professionals, the American Association of Occupational Health Nurses recently issued a letter on Genetic Privacy supporting the move to "prohibit discrimination based on genetic information in insurance and employment" (1). The American College of Preventive Medicine issued a policy statement on Genetic Nondiscrimination in Health Insurance and Employment that supports

> banning discrimination in hiring, compensation, and other personnel processes; prohibiting employers from requiring or requesting predictive genetic information; allowing genetic testing only to monitor the adverse effects of hazardous work exposures; and requiring predictive information possessed by employers to be confidentially maintained and disclosed only to the employee on request and to researchers. (3)

In addition, the American College of Occupational and Environmental Medicine has issued a position statement on Genetic Screening in the Workplace to provide to physicians practicing in the employment setting guidance on the potential

use and misuse of genetic tests. This statement "recognizes that the greatest potential for misuse of genetic testing in the workplace involves discrimination in employability and insurability" and that "the guiding principles for such testing should be voluntary, informed consent and confidentiality with due respect for autonomy, equity and privacy considerations of those tested" (2). The focus of such recommendations on occupational health professionals is particularly appropriate because they would normally be involved in the use of genetic testing in the workplace. The occupational health professional would traditionally be called upon to make medical decisions that directly affect employment status and would usually be responsible for the development of employer policies on the implementation, application, and uses of medical tests in the workplace and in the design, gathering, interpretation, and control of any medical information there. In lieu of clear-cut legal and regulatory guidelines on genetic testing in the workplace, professional responsibility becomes a critical bulwark against abuses. Unfortunately, it is not clear that occupational health professionals are adequately prepared to deal with the particular issues raised by genetic testing. Although in a national survey occupational medicine physicians expressed concerns about the ethical problems related to genetic testing in the workplace (7), their level of understanding of the ethical, legal, and social implications has not been directly assessed. Their knowledge in related areas appears to be less than optimal, however. For example, a survey of occupational medicine physicians in Minnesota, concerning their understanding of the requirement of job-relatedness in preplacement tests for prospective employees and of the release of their medical records, revealed a widespread lack of familiarity with the relevant ethical and legal principles (49).

In addition, the level of understanding of physicians in general of the use and interpretation of genetic tests has been found to be poor (17). In part, this is due to the limited attention devoted to genetics in medical school (29 hours of course work over the four years on average in the United States) (5) but is further compounded by the self-reported dramatic fall-off in adequacy of genetic knowledge among practitioners after graduation (42). In particular, appreciation of the ethical, legal, and social consequences of genetic testing is largely unsatisfactory, depending predominantly on self-directed learning and the coverage of these issues in the lay press rather than the scientific literature (17, 27). These concerns are supported in many studies. For example, in a study of genetic testing for the *APC* gene for colon cancer, physicians failed to obtain the necessary informed consent or provide genetic counseling for the majority of patients, and in a third of cases physicians incorrectly interpreted the test results (14). A survey of primary care physicians in the Pacific Northwest found significant deficits in familiarity with knowledge of genetics issues, although most respondents (55%) stated that they would provide genetic counseling themselves rather than referring patients to a specialist (21). A survey to determine Alabama's primary care physicians' knowledge, attitudes, and behaviors regarding cancer genetics found a general lack of confidence in dealing with genetic testing, as well as concerns among most (69%)

about the implications of genetic tests for their patients' employability, insurability, and emotional well-being; 92.2% of respondents were interested in learning more about genetics, including about guidelines for screening and interventions based on test results and helping patients make informed decisions to cope with fears and concerns (4). A survey of fellows of the American College of Obstetricians and Gynecologists found that 65.4% of respondents did not consider themselves well informed about genetics issues, and 86% did genetic testing without first soliciting informed consent (58). A focus group study of physicians, nurses, and counselors in the United States sought to identify the types of ethical and professional challenges that arise with genetic testing. Among the major issues identified were informed consent, withholding information, value conflicts, diversity issues, confidentiality, attaining/maintaining proficiency, professional misconduct, and discrimination (56). A needs assessment survey of general practitioners in Australia found that they felt inadequately prepared to manage patients with genetic conditions particularly in the areas of genetic testing and counseling (33). In these areas, there is no reason to assume that occupational medicine physicians differ, because, as noted above, their understanding in related areas is lacking (49) and their training in genetics no different. Therefore, reliance solely on professional understanding and decision-making to handle these problems is currently a risky proposition.

CONCLUSIONS

Genetic testing in the workplace is occurring now, and its use could increase greatly in the near future. Although there may be benefits for worker health from genetic testing, the risk of harm to workers from its misuse is real and significant. Current legal and professional responses are inadequate. Comprehensive federal legislation that affords real protections against the abuses of genetic testing in the workplace, as well as in other settings, is needed. Insuring that professionals are sufficiently knowledgeable about genetic testing and its risks and benefits is critical so that they can render appropriate advice and information. At a minimum, professional guidelines require that for genetic testing in the workplace to be done appropriately it should be done with the worker fully informed (including suitable genetic counseling) and completely free to consent (or not), and that access to the resulting information and control of its use be up to the individual tested. Under those circumstances, it may be possible for workers to undergo testing in a voluntary manner and to use the information from testing to make decisions about their job that may help prevent disease without sacrificing their privacy, autonomy, or dignity.

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