
Genetic Testing and Psychology

New Roles, New Responsibilities

Andrea Farkas Patenaude
Alan E. Guttmacher and Francis S. Collins

*Dana-Farber Cancer Institute
National Human Genome Research Institute*

Advances in genetics and genetic testing promise to catalyze a fundamental change in the practice of medicine. Psychologists have much to offer as psychotherapists, researchers, educators, and policymakers to a society heavily influenced by the genetic revolution. To make the most of new opportunities available to mental health professionals in genetics, psychologists must know basic genetic principles and learn what is new about 21st-century genetics. The core competencies for all health professionals developed by the National Coalition for Health Professional Education in Genetics are related in this article to the significant roles psychologists can play in helping individuals with genetic concerns to cope with vulnerability, optimize family interaction, and improve health behaviors.

Advances in genetics and genetic testing promise to catalyze a fundamental change in the practice of medicine (Collins & McKusick, 2001). Genetic advances have led to new approaches to the assessment of cancer risk and prevention recommendations for some currently healthy individuals (Burke, Daly, et al., 1997; Burke, Petersen, et al., 1997; Li, 1995; Weitzel, 1999), to pre-symptomatic genetic testing for Huntington's disease (Leavitt, Wellington, & Hayden, 1999), and to genetic predisposition testing for some cases of Alzheimer's disease (Saunders, 2000). The coming decades will see an explosion of information about the hereditary nature of disease susceptibility (Juengst, 1995). Genetic treatments and prevention strategies will be more fully integrated into clinical medicine over the coming decades as translation of research findings becomes possible for a wider and wider range of conditions. Deleterious genetic mutations being studied at the end of the 20th century were largely major alterations in single genes that affect relatively small numbers of people. In the future, scientists will come to understand much more clearly the interactions among genes and between genes and the environment that contribute to the causation of common disorders that affect a much larger percentage of the population. Biomedical advances will also increase understanding of genetic differences in pharmacological sensitivity between individuals, leading eventually to tailoring medications based on inherited characteristics (W. Evans & Relling, 1999).

The shift to greater understanding of the genetic basis of diseases is formulated on the international work of decoding the human genome (International Human Ge-

nome Sequencing Consortium, 2001). This knowledge will fuel development of powerful new technologies for determining gene expression and the ways in which alterations in genes affect protein structure and, ultimately, alter physiological function. This knowledge will also make it possible to distinguish varying forms of a disease on the basis of biological mechanisms of etiology rather than on symptomatology. This will in turn often allow for more effective approaches to prevention and treatment. This leap forward is analogous to the changes brought by the microscope, which greatly improved the ability to differentiate organisms responsible for disease and thus enabled physicians to treat different diseases by different, more appropriate and effective methods.

The genetic revolution stems from the new field of genomics, the study of the functions and interactions of all the genes in the genome. It takes advantage of innovations such as the ability to identify molecular alterations in disease genes. This revolution involves a basic change from treatment of disease based largely on symptom presentation to treatment and, eventually, prevention based to a significant degree on information available at birth in an individual's chromosomes. The result of this revolution is that individuals will have available to them much more specific prognostic information about their personal risk for many common diseases. The nature and significance of this information will vary greatly for different diseases, as progress is far from uniform. On the individual level, information about genetic health risks can now be accessed at more points in the life cycle than would previously have been possible. For instance, a young woman from a family

Editor's note. Barbara Andersen served as action editor for this article.

Author's note. Andrea Farkas Patenaude, Dana-Farber Cancer Institute, Boston, Massachusetts; Alan E. Guttmacher and Francis S. Collins, National Human Genome Research Institute, Bethesda, Maryland.

This article is based in part on an invited address by Francis S. Collins entitled "Medical and Social Consequences of the Human Genome Project," delivered at the 108th Annual Convention of the American Psychological Association in Washington, DC, on August 5, 2000, and on Andrea Farkas Patenaude's Rosalie G. Weiss Lecture entitled "DNA, Damocles, and Decision-Making" delivered at the 108th Annual Convention of the American Psychological Association in Washington, DC, on August 6, 2000.

Correspondence concerning this article should be addressed to Andrea Farkas Patenaude, Dana-Farber Cancer Institute, 44 Binney Street, Boston, MA 02115. E-mail: andrea_patenaude@dfci.harvard.edu

**Andrea
Farkas
Patenaude**



in which multiple cases of breast cancer have occurred might previously have worried about her chances of developing breast cancer but would have had no way of knowing for sure if she had an increased risk until she did or did not develop the disease in her 30s, 40s, or even later. This young woman may now be able to ascertain her genetic risk for breast cancer before starting a family rather than waiting to see if she develops cancer in her 40s or later. Psychologists will be critical in determining what the emotional outcomes of such changes are.

An issue of even greater psychological import is the emotional impact of coping with one's risk for a number of illnesses many years before the expected disease onset. In the case of hereditary colorectal cancer, for example, the differences between sporadic and hereditary disease include that "hereditary colorectal cancer requires an understanding of genetics, heredity, and the attendant mathematics of risk calculation, but, most importantly, there must be a belief that it is possible to remain healthy whilst having an increased risk" (Chapman & Burn, 1999, p. 118). Psychologists will again be in the research foreground. Here, their task will be determining how risk notification affects the attitudes and quality of life of those who use genetic technology and developing behavioral interventions to aid in coping with increased but still incomplete knowledge of risk.

Genetic knowledge has current clinical application most notably for certain cancers where single-gene mutations are responsible for much of the familial clustering and early presentation of disease. These areas of current clinical application illustrate the depth of the social and ethical implications of genetic advances. Genetic testing is available for breast, ovarian, and colorectal cancer and some

rare syndromes associated with increases in cancer risk (Li-Fraumeni syndrome, Von Hippel-Lindau syndrome, familial melanoma, and neurofibromatosis). Much will be learned by following individuals identified as having mutations that portend high risks of developing cancer. For example, the risk of breast cancer in women with known *BRCA1* and *BRCA2* (*BRCA1/2*) mutation is between 56% and 85% (Easton, Bishop, Ford, Crockford, & the Breast Cancer Linkage Consortium, 1993; Struewing et al., 1997), and the risk of ovarian cancer is between 20% and 60% (Gould, 1997; Struewing et al., 1997).

Although some genetic risk information involves relatively straightforward single-gene disorders, such as Huntington's disease or cystic fibrosis, the risk for many conditions will involve more complex equations involving multiple genes, environmental factors, or interactions between genes and environment. Careful assessment of health behaviors (e.g., smoking, diet, exercise, oral contraceptive and hormone replacement use) and biomedical and genetic factors in those at increased genetic risk can advance scientific understanding of what triggers breast and ovarian cancer development and, conversely, what prevents cancer from forming in some individuals with genetically increased risk. Greater understanding of such disease mechanisms can lead to new, targeted treatments. Studies of the value of drugs that may reduce breast cancer risk, like Tamoxifen or Raloxifene, and surgical or behavioral interventions targeted to those with increased risk can similarly add greatly to scientific understanding of the steps in cancer development and of the diagnostic factors of importance in making treatment or prevention decisions.

Even greater hopes rest on the potential utility of gene therapy to fix problems in gene structure and function that lead to cancer and many other diseases. Although these steps are, in most cases, many years in the future, more immediate is the targeting of pharmaceuticals based on an individual's genetic characteristics. This kind of individualized medicine, "the right drug for the right patient" (March, 2000, p. 20), will improve the efficacy of medication and decrease the morbidity of drug side effects. Just as bleeding with leeches is now looked at as a primitive approach to dealing with infections in the blood, a few decades hence current treatments may look gross and inappropriately homogeneous compared with targeted genetic treatments.

However, in considering this and many other aspects of the genetic revolution, it is important to recognize that the use of screening mechanisms, drugs, or prophylactic surgery targeted to those at increased hereditary risk will rest in large part on psychological factors governing acceptability of and adherence to recommendations. These factors include cultural and socioeconomic differences in attitudes toward genetics that affect uptake of targeted treatments. Psychologists will be important not only in understanding and addressing these differing views between groups but also in understanding what accounts for differences in views of genetics and related treatment recommendations among members of the same group or family.



**Alan E.
Guttmacher**

The benefits of the genetic revolution will extend not just to individuals with family histories of inherited disease. It is also important to realize that understanding the mechanisms underlying the etiology, prevention, and treatment of diseases in individuals who develop them partially as a result of inherited factors will also provide important insights into the etiology, treatment, and prevention of such diseases even in those who develop disease independent of inherited factors.

Changes in medicine change health care and, sometimes, society. Scientific understanding of the complex interactions that lead from genetic predisposition to disease presentation is still in its infancy for most types of disease. In most cases, identification of the genetic basis of a disease will predate improved ability to treat it, leaving many patients in a quandary about the value of having such personalized genetic information.

These advances in genetics will also change the clinical practice of psychology in many ways. Genetics will make finer and earlier distinctions between family members with known predisposition to a variety of serious and less serious illnesses. For example, in some families in which breast and ovarian cancer has occurred with higher than expected frequency, all the female blood relatives in the family may have considered themselves at high, if not certain, risk of developing these cancers. Genetic testing, if undertaken, may now divide the family into those truly at increased risk and those without the *BRCA1/2* mutation who are only at the population risk of approximately 10%. Family members with deleterious mutations have to worry not only about cancer in themselves but also about a significant risk of passing on these mutations to their children and grandchildren, whereas family members without such mutations will be spared these fears. Further genetic

and genomic developments may also divide women at increased risk into two groups: those for whom new drugs offer promise of prevention and those who are not genetically suited to the drugs who may be advised to consider prophylactic surgery, with its attendant emotional costs.

Such genetics-based distinctions, all of which may occur prior to any disease presentation, are likely to have major implications for emotional well-being (optimism, depression, anxiety) and for developmental life planning (whether to marry, when or if to have children, whether to plan extensive educational preparation for a career). In addition, emotional and financial security may be threatened if employers or insurers have knowledge of such individual risks. As more individualized risk information becomes available, societal and familial expectations of the degree to which high risks can and should be controlled may also change. This may put pressure on some individuals to act in ways that are not consistent with their health beliefs and life outlook. The rapidly changing knowledge in this area may frustrate some people who, in their attempt to do all that is possible, may take actions or make decisions that, with the availability of new genetic or treatment information, they later regret. Others may be disappointed that knowledge of gene status does not lead to prevention or cure in their lifetime. Anxiety about genetic health risk may occur in many people for whom genetic testing or treatment is not yet an option. This anxiety may be due in part to misconceptions about current genetic knowledge, fueled by some overly optimistic press reports (Petersen, 2001).

New fields of psychological research are emerging that mirror the growth of new areas of biomedical understanding. Research is underway, much of it under the auspices of the Ethical, Legal, and Social Implications Program of the Human Genome Project, on cognitive barriers to understanding complex genetic information and cultural and demographic variation in the acceptance of genetic information. Psychological research can in part answer questions about the value and potential risks of having predictive genetic health information, especially when little is known about what can be done to avoid the illness in question. For instance, how will people understand the differences between a very small inherited risk of cardiac disease, conveyed by one of many contributing genes and mediated by a number of other genetic and environmental factors, and the much greater increase in risk for breast and ovarian cancer conveyed by mutations in *BRCA1/2*? How will decisions be made about when to seek predictive genetic information? Will some people find that genetic testing leads to having too much medical information? How will family communication and interaction be altered? How will the availability of such information change ideas of health and health behavior practices?

How people are informed about their predisposition to disease and about prevention and treatment options and how much they understand of this complex information will have a great effect on their willingness to accept treatments based on genetics and genetic testing (Marteau, 1999). Behavioral and clinical psychologists have a major



Francis S. Collins

role to play in helping to maximize people's willingness to consider preventive interventions and to cope with the emotions evoked. Research can help determine the optimal times and ways to approach individuals about, for instance, testing for a number of genetic factors in cardiac disease. By tailoring the presentation of genetic information, behavioral scientists can help explain interventions to individuals of different ages, reducing attendant anxiety. Reduction in anxiety may in turn aid the adoption of health behaviors, such as exercise or diet, or the willingness to take medication targeted to those most at risk. In many respects, psychological factors governing willingness to undergo genetic screening or testing and to follow preventive recommendations will determine much of the ultimate utility of the findings of Human Genome Project scientists.

This article describes many of the ways in which new genetic knowledge will affect the roles of psychologists inside and outside medical settings. New roles, however, involve the responsibility to incorporate new knowledge. Many professional groups are devoting considerable effort to providing training in new areas of genetic knowledge for their members. The National Coalition for Health Professional Education in Genetics (NCHPEG), an organization representing over 120 health professional societies, took on, as part of its mission, the definition of core competencies that form the basis of effective functioning in this new area for all health professionals (Jenkins et al., 2001, and available online at <http://www.nchpeg.org>). This article reviews those competencies and links the NCHPEG recommendations with the clinical and research skills psychologists will find it useful to possess in coming decades.

New Roles: What Can Psychologists Do in the Genetic Revolution?

Clinical Service Opportunities

Clinical psychologists may find it difficult to appreciate how fundamentally the genetic revolution will affect their practice. As genetic knowledge grows, more and more individuals seeking the care of a psychologist will bring concerns about inherited physical or emotional vulnerability.

Until recently, genetic counseling and testing were of use almost exclusively in two situations: prenatal reproductive decision making and relatively rare disorders due to mutations in single genes. Medicine has entered a new era, however, in which genetic counseling and testing will be of use for many at risk for common disorders. Some estimate that 20 diseases account for 80% of the deaths in the Western world and that these diseases are due to the influence of 100 to 200 genes, all of which should be identified within a few years (Roberts, 2000). Fifty to one hundred thousand cases of cancer per year are attributable to inherited susceptibilities (Klausner, 1998), and there are estimates that a quarter of a million people are now appropriate candidates for cancer genetic testing (Offit, 1998). Beyond these individuals are thousands of other cancer patients and their relatives who worry whether the cancer in themselves or their family members has a hereditary basis. Because of the heavy media coverage of genetic breakthroughs, many individuals are aware of the connection between cancer and heredity. Many fewer appreciate that only 5% to 10% of cancers are clearly traceable to strongly acting inherited mutations. As more cancer genes are identified, the number of individuals for whom cancer genetic counseling can provide useful answers will grow. However, another effect of the media attention that will undoubtedly accompany such advances is increased anxiety among a wider circle of individuals. For many of these individuals, genetic counseling and testing may not be able, for one reason or another, to provide even relative certainty about their personal cancer risk. Many individuals receiving test results will seek the services of clinical and health psychologists to address personal and familial issues that arise as a result of knowing their genetic status. Many other individuals for whom answers to questions about their genetic risk are unavailable may also seek psychological counseling to manage their anxiety and uncertainty.

Anxiety about the genetic basis for diseases that threaten quality of life will similarly increase as research points to early genetic markers as precursors of those diseases. For example, recent research on neurologically normal individuals with increased hereditary predisposition for Alzheimer's disease showed differences in brain activation patterns between these participants and controls without hereditary predisposition (Bookheimer et al., 2000). These results suggest that physiological changes begin considerably before the onset of neurological symptoms in individuals at increased genetic risk. Such research is likely to raise questions for many people about whether and when they should seek genetic testing for predisposi-

tion to Alzheimer's disease and how they would handle the results of such testing.

Because each individual is thought to have dozens of mutated genes (Collins, 1999) that influence risk for common disorders such as cancers, atherosclerosis, diabetes, or mood disorders, it seems highly likely that anxiety about genetic aberrations, future disease, and reproductive consequences will concern a growing segment of the general population. Psychologists will be consulted about these issues, either specifically in consultation about whether to pursue genetic counseling or testing or to adopt prophylactic measures, or as part of broader psychological treatment.

Variant genes are a unique disease mechanism in that they are shared by biologic relatives. When a family member is diagnosed with a condition in which inherited factors play a significant role, family relationships are affected even more than they are in other forms of illness (Dudok deWit et al., 1997; Jacobs & Deatrick, 1999). Concern is raised not only about the affected individual but also about the consequences for other family members. Identification of a genetic predisposition in one family member, even in the absence of disease, raises many questions about how to communicate such information within a family and often triggers new alliances and disagreements within the family. Such alterations are grist for psychologists' mills. Family and marital therapists will find patients' anxieties and angers increasingly intertwined with genetic concerns. Psychologists who focus on areas such as adoption or developmental disabilities will find more concern about a child's hereditary makeup among biologic parents or potential adoptive parents.

Similarly, behavioral psychologists who focus on helping individuals to abandon unhealthy behaviors and adopt those that are known or thought to improve well-being and lengthen life span will increasingly need to know about the genetic factors that influence well-being and longevity, as well as those relevant to the adoption of health behaviors. Interesting current research focuses on mutations that may affect how early a person initiates smoking behavior and how likely he or she is to be able to stop smoking (Lerman, 2000). Weight loss research may benefit from increasing awareness of genetic factors in obesity (Zhang et al., 1994). Knowledge of such individual differences will, it is hoped, trigger the development of targeted interventions, which may increase the efficacy of smoking cessation or weight loss programs or other health behavioral strategies.

As genes that affect the development of psychiatric conditions such as mood disorders, schizophrenia, attention-deficit hyperactivity disorder, and so on are found, the need for psychologists who are knowledgeable about the genetic findings, as well as about diagnosis and, potentially, pre-symptomatic treatment of these disorders, will grow enormously (Faraone, Tsuang, & Tsuang, 1999). Genetic counselors and mental health practitioners will need to work closely together to develop counseling methods appropriate for psychiatric conditions with genetic features.

Psychologists play a major role in research on the genetics of psychiatric disorders. One crucial aspect of that

role is the careful elucidation of diagnostic criteria in studies seeking clues to the genetic underpinnings of mental disorders (Owen & Cardno, 1999). Without such careful definitions, the research is likely to lack the specificity necessary to determine whether genetic factors are at work in the etiology of these conditions. Another aspect of that role is that clinical psychologists can help patients and family members understand that although they are being asked to participate in research on the genetics of mental illness, scientific knowledge is not yet at a point where such research has direct clinical application for most affected families. The frustration of the limitations of current knowledge will remain a problem for families with hereditary predisposition to both physical and mental illness for some time, and psychologists can play a key role in helping individuals and families cope with this frustration.

Research Opportunities

Research on psychosocial implications of genetic advances is becoming an area of great interest and is bolstered by support from the five percent of the budget of the Human Genome Project devoted to ethical, legal, and social issues (Jeffords & Daschle, 2001). New areas of research opportunity for psychologists in the area of genetics build on prior studies of emotional outcomes, communication, family relationships, and psychological factors that influence the adoption of health behaviors. Advances in genetics will emphasize the importance of dealing with individualized disease predispositions and targeted disease prevention. The resulting need to develop preventive programs for those at increased genetic risk for disease will increase the utility of quantitative and qualitative data on how people understand risk, how they communicate within families about medical issues, and how awareness of risk is or is not related to taking good care of oneself. As larger and larger segments of the population are offered information about their personal risk for a broad range of diseases, it is imperative that psychologists understand what makes a person want to have or to avoid such information and what use he or she is likely to make of it (Lerman, Daly, Masny, & Balslem, 1994; Lerman et al., 1998). Although the autonomy of an individual's right to take or not take such information when offered remains paramount, psychological research can determine if a decision is based on adequate comprehension of complex material and if the decision is consistent with the individual's culture, values, beliefs, and emotions. Research can suggest more effective counseling strategies (Marteau & Croyle, 1998). Development of interventions that improve comprehension, relieve distress, foster conscious autonomy, and improve uptake of healthy behaviors is among the goals of psychological research in genetic medicine (Hopwood, 1997).

If individuals in coming decades are to receive genetic "report cards," that is, printouts of the genes they carry that bear deleterious or beneficial mutations, it will be important to present the information in ways that optimize comprehension. There are many different levels of identified genetic risk information. In some cases, only a marker will be known for genetic disease, offering much less accurate

predictive information. In other cases, predisposition testing for major genes may offer relatively clear answers to some individuals about their risk for disease. Still other situations could involve a mire of minor genes and environmental risks that may not for many years hence provide clear, predictive, or preventive information. Perception of statistical risk is notoriously poor, even among members of high-risk families with single-gene mutations, the least complex of the genetic circumstances (D. G. Evans, Burnell, Hopwood, & Howell, 1993; Lerman, Seay, Balshem, & Audrain, 1995), and it is subject to a variety of influences that lead to misunderstandings (Kahneman & Tversky, 1979). Developmental considerations further complicate thinking about how to talk to children and teenagers about genetic risk. Psychologists have considerable expertise in these areas, expertise that can be usefully applied to understanding how people receive the growing body of genetic information offered to the public.

Understanding the cultural and ethnic import of sensitive information about inheritance can also improve communication about genetic risk to minority and traditionally underserved populations (Foster, Eisenbraun, & Carter, 1997–1998). Genetic research on human variation is also likely to stir emotions about genetic inclusion or exclusion among members of racial and ethnic groups. Research results in this area have direct application to the development of genetic counseling modules that maximize comprehension and convey personal and ethnic sensitivity.

Psychologists have long studied family interaction. The growing role of genetics in medicine suggests that how family members communicate with each other about illness and genetic susceptibility will have considerable impact on how genetic information is spread and utilized (Glanz, Grove, Lerman, Gotay, & LeMarchand, 1999; Julian-Reynier et al., 1996; Patenaude, 2001). In collaborative work with genetic counselors, psychologists have much to offer in improving understanding of family communication about genetic matters and in helping to reduce related familial distress.

The advent of genetic testing for Huntington's disease and cancer aroused much concern about how individuals would react to receipt of their genetic test results. The study of genetic testing outcomes is still in its infancy, but results suggest complexity in individual response. Early reports of short-term outcomes relying on group means on standard psychological measures showed relatively low levels of distress, offering general reassurance that disastrous psychological consequences, such as suicide, were unlikely (Croyle, Smith, Botkin, Baty, & Nash, 1997; Harper, Lim, & Craufurd, 2000; Lerman et al., 1996). More recent reports have indicated that disclosure of the presence of a *BRCA1/2* mutation is more upsetting than anticipated to a subset of individuals including, particularly, many cancer patients (Dorval et al., 2000). Other studies have shown that an individual's response to receipt of his or her own test result differs by the involvement or lack of involvement of other family members in testing and by the results received by tested relatives (Smith, West, Croyle, & Botkin, 1999). Psychologists with a variety of skills in both

quantitative and qualitative research methods will be needed to tease out the answers to questions about how individuals react emotionally to learning their genetic risk status.

The goals of the genetic revolution will be fully accomplished only if improved understanding of genetic risk leads to improvements in the general health of the population. Although physicians do not yet have many clear preventive health recommendations for carriers of disease gene mutations, with time this will change considerably. Psychologists have much to offer in improving understanding of how notification of genetic risk affects an individual's health behaviors and utilization of risk-reducing options. It is likely that no one approach is optimally effective in communicating genetic information to and inspiring healthy behaviors in both men and women, in both old and young, and in individuals of different cultures. Studies of decision making among individuals at different levels of risk and of different genders, ages, and ethnic groups will foster development of targeted approaches. In addition, tailoring of health recommendations for those at increased genetic risk will need to take into consideration personality differences between those who seek health information (monitors) and those who actively avoid anxiety-provoking news about their health (blunters; Miller, Shoda, & Hurley, 1996). Of utmost importance will be studies of the efficacy of various interventions to groups and individuals with particular characteristics and studies of the role of emotions, life experience, coping style, and other factors in guiding health decisions related to knowledge of genetic risk.

Psychologists' Roles in Discussions About the Ethics of Genetic Testing

Genetic advances bring to light many ethical quandaries (Wilfond, Rothenberg, Thomson, & Lerman, 1997). Psychologists in both clinical and research roles have much to contribute to societal and individual discussions about these ethical questions. Ethical issues in genetic medicine range widely from when it is ethical to offer genetic tests to what information people should be given about the limitations and risks of testing, who should be informed of genetic testing results, and whether there is a duty to recontact patients when new genetic information about their status arises. There are also ethical questions about professional roles in the handling of genetic information and about societal pressure for people to adopt healthy behaviors if they are at known genetic risk. Questions about employers' access to information about genetic status for purposes such as determining an individual's job fitness or estimating potential health problems of the employee raise the need for legislation to protect workers. The issue of insurers' access to genetic test results raises other ethical dilemmas and societal issues.

The fact that genetic testing of a single individual reveals information of potential relevance for other family members puts new pressures on family members to act altruistically in the interests of other, sometimes distant or estranged relatives (Patenaude, 2001). The ability to give

informative results often rests on the willingness of an affected family member (one who has had the disease) to be tested. Such testing is necessary to determine the presence, location, and nature of the familial mutation, thereby allowing examination of the unaffected relative's DNA for the same mutation. A woman whose mother died of breast cancer may need to ask her elderly aunt, who is herself many years past her breast cancer diagnosis, to be tested. The aunt may initially agree to be tested and yet, when she comes for genetic counseling, may find that she has deep misgivings about opening what she perceives to be a Pandora's box full of the potential for feelings of guilt and fear. She in truth does not wish to be tested. This circumstance raises questions of individual rights and professional roles. A clinical psychologist, working in conjunction with the genetic counselor, may provide useful services in talking with the aunt and possibly with the niece and helping to find a resolution that respects autonomy, improves understanding of the emotions of all parties, and works to insure that family relationships are preserved.

On a larger level, psychologists can have input into the roles of genetics professionals in matters that affect families. In 1998, the American Society of Human Genetics suggested that in exceptional cases where a patient refuses to inform relatives of a serious genetic risk to their health, the genetics professional has a right and a responsibility to override the patient's confidentiality and inform the relatives of the genetic risk (American Society of Human Genetics Social Issues Subcommittee on Family Disclosure, 1998). (Consider a situation, for example, in which familial hypercholesterolemia is discovered in an individual who decides not to inform ["upset"] any relatives. Uninformed family members might not be motivated to take advantage of routine cholesterol testing and might have heart attacks resulting from their hypercholesterolemia levels.) Psychologists experienced in family research and intervention could suggest methods of approaching such dilemmas that minimize harmful outcomes and lead to data-based policy recommendations about the handling of genetic information.

Psychological research can help with other ethical quandaries related to genetic testing. As data accumulate on the potential medical benefits of prophylactic mastectomy for *BRCA1/2* carriers (Hartmann et al., 1999; Meijers-Heijboer et al., 2001), doctors continue to caution that such drastic surgical intervention is not for everyone (Eisen & Weber, 1999, 2001). Psychological research can determine what characterizes women for whom this is an acceptable, even desirable procedure and women for whom it is likely to be emotionally debilitating. From such data, effective psychological interventions to aid women and professionals in the decision-making process can be developed.

Public Policy Opportunities

Another new area of opportunity for psychologists is the provision of expertise about psychological ramifications of genetics knowledge and genetic testing to legislators and other policymakers. Legislation about privacy, insurance coverage for genetic services, equal access to genetic ser-

vices, discrimination in employment and insurance, and other related topics will require a core group of mental health professionals with knowledge of such complex areas. United States Supreme Court Justice Stephen Breyer has clearly stated the needs of the courts for education about genetics in preparation for the many legal issues involving genetic considerations that they are likely to confront in the future (Breyer, 2000). Judges and lawyers will need information about the impact of knowledge of carrying a potentially deleterious genetic mutation on an individual's emotional functioning. The roles of genetic and psychological factors in susceptibility to criminal behavior and mental illness will be of great importance in legal determination of culpability.

Psychologists also have potentially useful contributions to make in development of social policy in areas such as adoption, involvement of children in genetic testing and other informed-consent issues, access to genetic services, and public education about genetics. Upset and upheaval are likely to accompany the societal change that growth in genetic knowledge is bringing about. Psychologists and sociologists who study the impact of change and adaptation to new information will have a role in helping those making rules for this changing society to understand how threatening such new information can be, especially when it relates to such basic human concerns as reproduction and physical and mental illness.

New Responsibilities: Genetic Education for Psychologists

To take advantage of new opportunities available to psychologists and other professionals by virtue of advances in genetics, professionals must commit themselves to learning what is new about genetics in the 21st century. Each profession has its own areas of study and expertise related to genetics, requiring different types and levels of inquiry and learning. However, all professionals will need at least a basic knowledge of genetics if they are to offer global understanding of the concerns of their patient population or research participants.

The goal of such education is not to make the roles of psychologists and genetic counselors interchangeable. The two disciplines differ in numerous ways, including the in-depth genetics training that is required of genetic counselors. The goal is rather that psychologists understand basic genetics concepts so that they can guide patients appropriately in resolving their concerns. Patients may require psychotherapy for resolution of emotional concerns, genetic counseling for resolution of medical concerns, or some combination of the two. To be comfortable with the genetic concerns of their patients, psychologists must revisit their knowledge of Mendelian genetics and also understand generally such concepts as penetrance and gene-gene and gene-environment interaction, which are prominent features of the new genetics. Also necessary is an understanding of the fact that genetic investigation has a range of possible outcomes and that both significant and trivial health risks are associated with different genetic

mutations. Psychologists can help patients understand what is involved in considering genetic testing or research involvement and what patients need to know to make a decision about pursuing testing or participating in research.

As with other health care specialties, psychological clinicians should know enough about the variety of genetic services to be able to make appropriate referrals for their patients. They should understand the role of the genetic counselor (and the limits of that role) and the special confidentiality concerns related to knowledge of genetic status. Psychologists should have knowledge of what genetic tests may reveal. They should also understand that patients need information prior to testing about who will have access to results and what the legal protections are for genetic information. Psychologists do not need to know the answers to all questions about genetic testing posed by their patients; rather, they need to understand generally the limits and risks of testing and to know the kinds of questions that should be asked of providers. Usually, it will be the role of genetics professionals to supply these answers.

Genetic counselors routinely do brief assessments of patients' emotional status and motivation for testing to determine if the patients' expectations of genetic testing are realistic. They also attempt to judge if the process of genetic counseling and testing is likely to arouse particularly high levels of anxiety and distress in their patients. When concerned by the level of distress or by unusual psychological features of a patient, most genetic counselors will make a referral to a mental health professional for more in-depth assessment. The psychologist or other mental health professional can offer a more thorough assessment of the psychological vulnerability of the patient and can characterize the presence or absence of psychopathological features. The mental health professional is likely to have more time and expertise with which to ascertain the level and nature of the distress, to assess the person's coping style and emotional resources, and to take a detailed psychiatric history than is the genetic counselor. Taking into consideration the genetic counselor's assessment of the range of likely genetic testing outcomes, the psychologist can make a recommendation about whether the patient's current level of distress and his or her personality and defensive structure are sufficient to cope with the potential stresses of testing. Psychological treatment, concurrent with genetic testing, may be advised; in selected cases, it may be recommended that testing be postponed until the current distress is resolved or the psychiatric illness treated.

Core Competencies

The National Coalition for Health Professional Education in Genetics (NCHPEG) is a multidisciplinary group dedicated to enhancing genetic knowledge among all health professionals. NCHPEG began in 1996 to develop coordinated approaches to improving health professional education about genetics and to provide access to information about genetic advances. NCHPEG represents over 120 member organizations, including professional groups serving medicine, genetic counseling, psychology, nursing, social work, dentistry, nutrition, psychopharmacology, and

many others. The American Psychological Association is a member of NCHPEG.

Although it is not a standard-setting or regulatory organization, NCHPEG has sought to define core areas of knowledge, skills, and attitude about genetics that are important for all health professionals. (The core competencies that NCHPEG formally approved [Jenkins et al., 2001], with input from its Steering Committee members, can be seen online at <http://www.nchpeg.org>.) Given that professionals in different disciplines perform highly varied roles with regard to patients' genetic concerns, NCHPEG recognized that it is a particular challenge to define core competencies that apply to all. However, NCHPEG felt that

Competency in these areas represents the minimum knowledge/skills/attitudes necessary for health professionals from all disciplines (medicine, nursing, allied health, public health, dentistry, psychology, social work, etc.) to provide care to their patients that involves awareness of genetic issues and concerns. (Jenkins et al., 2001, p. 156)

Genetic knowledge is changing very rapidly. Although the NCHPEG core competencies describe a need to keep abreast of new information, the breadth of professionals' genetic knowledge will vary with the degree of their professional involvement in this area. We briefly review the NCHPEG core competencies with particular reference to psychologists.

Knowledge

To work clinically with patients confronting issues related to genetics, mental health professionals need to have at least a basic knowledge of the role of genetic factors in health and of the basic principles of inheritance. Patients want providers to whom they do not need to explain the basics of genetic information. Specialists working closely with high-risk populations or carriers of deleterious mutations need in-depth knowledge of the relevant genes and their function, prevalence, penetrance, and inheritance pattern. However, all psychologists should possess sufficient knowledge of the patterns of inheritance so that a patient can explain the particulars of his or her family history and concerns about inherited disease without having to review basic concepts. All psychologists should also appreciate the health implications of one family member's genetic test results for their patient and for other close relatives. All psychologists should have sufficient awareness of relevant state and federal laws regarding genetic privacy and the potential for discrimination so that they can appropriately discuss issues such as what they will record in the patient's medical record or in their treatment notes. Particularly as genetic testing becomes more prevalent, psychologists will need to understand the complex process of appropriate informed consent for genetic testing. They will need to do so both because they will sometimes refer patients for such testing and because sometimes other health professionals will ask them to assess the psychological readiness of individuals for genetic testing or to help individuals prepare for and deal with such testing.

Skills

Psychologists should know when to suggest genetic counseling to a patient, know how to explain what the genetic counseling process entails, and be able to help patients locate needed genetic services. They should be able to consult as desired with genetic specialists, remaining mindful of the importance of confidentiality in this area and the need to involve patients in decisions about the extent of the psychologist's involvement and discussion with other professionals. Occasionally, a mental health professional may accompany a patient to his or her results-disclosure genetic counseling session (Massie, Mushkin, & Stewart, 1998). Good clinical skills are required to determine when such action is warranted and appropriate for a particular patient.

Psychologists should be able to help patients understand relevant genetic information and should know how to access genetic support groups or other services if further help is needed. Given the vast amount of genetic information available on the Internet, it is useful for mental health professionals to be able to direct patients seeking further knowledge to legitimate resources. Psychologists may offer appropriate cautions to certain patients about the potential distress they might feel from exploring what could be highly charged information without the support of appropriate professional relationships. A psychologist might, for example, suggest for some patients that they seek the desired information in the context of genetic counseling rather than in the isolation of a Web-based search.

Attitudes

In few areas is the therapeutic neutrality of the psychologist as important as in dealing with genetic issues. Feelings aroused by genetic information are deep and long lasting. They include guilt for passing on mutations to children, blame directed at partners for having done so, guilt for not sharing information about hereditary predisposition to disease with siblings, and anger at receiving bad mutations from parents. Genetic information can also raise fear about illness and death, concern for the health of relatives, and anxiety about whether to undergo "disfiguring and potentially psychologically damaging" (Eisen & Weber, 1999, p. 138) prophylactic surgery. Patients need an accepting atmosphere in which to experience these difficult emotions and to make decisions about seeking and using genetic information. They may be cut off from usual support from family members because of the intertwining nature of genetic concerns and may be all the more reliant on the holding environment provided by the therapist.

Therapists may have strong feelings themselves about the correctness of some of the steps contemplated by their patients, such as prophylactic mastectomy or planning not to tell some family members about the presence of a genetic predisposition to serious illness. Therapists and researchers must rely on their training and experience to avoid undue interference from emotions that result from countertransference. The NCHPEG core competencies emphasize appreciation of the sensitivity of genetic information and the importance of counseling that is free of coer-

cion or bias. They stress the importance of recognizing when "personal values and biases with regard to ethical, social, cultural, religious, and ethnic issues may impact or interfere with care provided to clients" (Jenkins et al., 2001, p. 157).

A further issue addressed in the NCHPEG core competencies is the recognition of the limits of one's genetics expertise. Given the breadth of knowledge currently available in genetics and the rapid rate at which new information appears, no one person can encompass knowledge of the entire field. Although some psychologists work intensively with genetics professionals, they do not possess the same skills. In a few exceptional cases, psychologists have undertaken advanced training in genetic counseling. A few genetic counselors are also certified as marriage and family therapists. Overlap in the issues included in the professional interchange with patients by medical geneticists, genetic counselors, and psychologists sometimes blurs professional boundaries. However, open communication between professionals can clarify the boundaries of professional involvement. Mutual consultation typically yields a better outcome for the patient and a more satisfying, edifying, and mutually respectful experience for the professionals.

Case Examples

Hypothetical examples of patients who might come to the attention of psychologists may help clarify roles for psychologists in the era of the new genetics.

Case 1: Walter

Walter is a 31-year-old man with a history of alcoholism and anxiety disorder. Now successfully abstinent from alcohol in his third year of Alcoholics Anonymous, he still finds himself unable to reduce his two-pack-per-day cigarette habit. Worsening shortness of breath has led to a medical evaluation, resulting in a diagnosis of early emphysema. Further evaluation reveals that he suffers from alpha-1-antitrypsin deficiency, a recessively inherited genetic disorder. Individuals with this condition typically develop emphysema in middle age, but onset and progression are clearly worsened by cigarette smoking.

All of this information has greatly heightened Walter's anxiety. He knows that continued smoking will hasten his lung damage. His physician mentioned something about gene therapy being possible in the future, and, at times, Walter seems to have unrealistic ideas about how imminent this rescue might be. It is actually rather unlikely for such treatment to be developed in time to help Walter, given that Walter's lung tissue is already being destroyed and that it will take years to develop and test an effective gene therapy.

A major dilemma for Walter is that he has three younger siblings, all of whom are smokers. His physician told him that he should encourage them to get tested because each of them is at a 25% risk of having the same deficiency. However, Walter's relationship with them is strained, and he does not want to reveal this new information about his illness, feeling that his siblings will just see

this as one more indication that he is defective in some way.

This case presents numerous challenges to the therapist—supporting Walter as he absorbs knowledge of his genetic risk and considers the relative role of genetics and smoking in his having emphysema, helping him to be realistic about whether there is a rescue in sight, encouraging his impulses to stop smoking without his slipping back into other forms of abusive behavior, and working with him to think through an approach to his siblings that would give them a chance to hear this important information while preserving his self-esteem. In treatment, Walter recognizes that his sense of concern for his siblings is mixed with a pervasive feeling of having gotten all that is worst in his family, including this genetic deficiency. Although he would like to warn his siblings of their genetic risks, he is also aware that medical evaluations might show him to be the only sibling to have inherited this predisposition, which he thinks would further confirm the sense of unfairness and jealousy that characterizes his feelings about his brothers and sister. Not telling them anything, though, would make him feel like a “bad person.” Walter makes an initial contact with his next younger brother to talk to him about the alpha-1-antitrypsin deficiency. It goes badly, as the discussion reverts to difficult past issues between them. Walter decides definitively not to talk to his siblings at all about his medical issues and the family’s shared genetic risk. When Walter’s physician tells him that he, the doctor, may have some responsibility for informing Walter’s brothers and sister about their risk if Walter is unwilling to (see American Society of Human Genetics Social Issues Subcommittee on Family Disclosure, 1998), Walter becomes very angry and anxious. His sense of panic and fear of losing control increase. The therapist ultimately plays a central role in consultation with Walter and his physician, who ultimately reconsiders, at least for now, his duty to warn Walter’s siblings.

Case 2: Susie

Susie, a 40-year-old mother of two daughters, is in the process of getting a divorce. There is considerable bitterness in the divorce proceedings. Susie has been seeing a therapist for about a year. Much of the work focuses on Susie’s depression related to the divorce and other earlier losses. Her mother died at age 42 of breast cancer when Susie was 16. Susie has been quite depressed of late and has been finding it difficult to get up in the morning to get her daughters off to school. She has sleep difficulties that she and the therapist hope to improve with relaxation training. Susie’s first cousin in another state has recently begun genetic counseling to learn if she is eligible for *BRCA1/2* testing. Susie thinks she would also like to undergo genetic counseling, although she is not sure how to go about finding a counselor. She thinks some of her depression may have to do with fears about developing cancer at an early age, especially because her husband is challenging her for custody of her daughters. She hopes genetic testing, if negative, might relieve her of her worries about dying early of breast cancer and about leaving her

daughters without a caretaker she considers adequate. She also hopes such a result would relieve her of her present worry that she may have passed this same increased risk for cancer to one or both of her daughters.

The therapist’s work with Susie involves multiple tasks and would be greatly enhanced if he or she possesses some knowledge about genetic testing for breast cancer. For instance, it is important that the therapist realize that a mutation in *BRCA1* or *BRCA2* increases risk not only for breast cancer but also for ovarian cancer so that he or she can help Susie appreciate the breadth of potential risks. The therapist needs to evaluate the level of Susie’s depression and to help her appreciate that receipt of a positive test result might deepen her distress. The therapist may not know the odds of finding a *BRCA1/2* mutation in Susie’s family but will need to caution Susie about the possibility that a mutation might not be found and to explore her feelings if testing produces such an indeterminate result. The therapist and Susie may discuss how much of Susie’s desire for testing she wishes to have in her record. The therapist may dislike the idea of only reporting part of their conversation but would recognize the sensitivity of the information. Because the therapist could be subpoenaed to testify at the divorce hearing, issues of limits to the confidentiality of their relationship would be of special concern. Although the therapist may feel that genetic testing poses considerable threat to Susie emotionally and legally, it is important that personal feelings are differentiated from professional judgment about Susie’s well-being because testing holds considerable interest for Susie. Consultation by the therapist with a genetic counselor knowledgeable about cancer may allow the therapist to answer specific questions about the counseling process and to inform Susie about how information obtained during genetic counseling is likely to provide a firmer basis for deciding on the advisability of genetic testing. If the therapist were able to suggest a particularly sensitive and helpful genetic counselor that he or she had previously worked with, Susie would likely experience this as a positive, supportive step in her search for more information about her cancer risk. It is also to be hoped, however, that Susie would take seriously the therapist’s cautions about further evaluating and possibly treating her depression before proceeding to genetic testing.

Conclusion

Psychologists have much to offer as psychotherapists, researchers, and educators to a society heavily influenced by the genetic revolution. Psychologists are trained to help people deal with many of the concerns highlighted by the growing ability to define personal genetic risk. These concerns include feelings of vulnerability to illness and defenses against mortality, varying concepts of time and culture, and family relationships. Psychologists help people identify and remove barriers to healthy, productive living.

To make the most of the new roles available to mental health professionals because of advances in genetics and genetic testing, psychologists need education about basic genetic principles and information about recent advances in

genetics. They need to understand the nature and implications of these advances and, at least in general, the potential social and emotional risks and benefits of genetic testing. Good clinical and research skills, based on solid training experiences, are the cornerstone upon which psychology's potential contribution to genetics rests. The inclusion of genetics in graduate school curricula, in licensing exams, and as part of standard psychological training will help produce adequate numbers of psychologists to meet the growing demand for mental health professionals who are knowledgeable about genetic issues. The NCHPEG core competencies outline the knowledge, skills, and attitudes that will allow 21st-century psychologists to assume valued roles in the community of providers offering support for genetics services and conducting research to maximize the medical and quality of life outcomes of genetic medicine.

REFERENCES

- American Society of Human Genetics Social Issues Subcommittee on Family Disclosure. (1998). ASHG Statement: Professional disclosure of familial genetic information. *American Journal of Human Genetics*, 57, 1233–1236.
- Bookheimer, S. Y., Strojwas, M. H., Cohen, M. S., Saunders, A. M., Pericak-Vance, M. A., Mazziotta, J. C., & Small, G. W. (2000). Patterns of brain activation in people at risk for Alzheimer's disease. *New England Journal of Medicine*, 343, 450–456.
- Breyer, S. (2000, May 12). *Genetics and legal institutions*. Talk presented at the Whitehead Institute for Biomedical Research, Cambridge, MA.
- Burke, W., Daly, M., Garber, J., Botkin, J., Kahn, M. J. E., Lynch, P., McTiernan, A., Offit, K., Perlman, J., Petersen, G., Thomson, E., & Varrichio, C. (1997). Recommendations for follow-up care of individuals with an inherited predisposition to cancer: II. *BRCA1* and *BRCA2*. *JAMA*, 277, 997–1003.
- Burke, W., Petersen, G., Lynch, P., Botkin, J., Daly, M., Garber, J., Kahn, M. J. E., McTiernan, A., Offit, K., Thomson, E., & Varrichio, C. (1997). Recommendations for follow-up care of individuals with an inherited predisposition to cancer: I. Hereditary non-polyposis colon cancer. *JAMA*, 277, 915–919.
- Chapman, P. D., & Burn, J. (1999). Genetic predictive testing for bowel cancer predisposition: The impact on the individual. *Cytogenetics and Cell Genetics*, 86, 118–124.
- Collins, F. S. (1999). Shattuck lecture: Medical and societal consequences of the Human Genome Project. *New England Journal of Medicine*, 341, 28–37.
- Collins F. S., & McKusick, V. A. (2001). Implications of the Human Genome Project for medical science. *JAMA*, 285, 540–544.
- Croyle, R. T., Smith, K. R., Botkin, J. R., Baty, B., & Nash, J. (1997). Psychological responses to *BRCA1* mutation testing: Preliminary findings. *Health Psychology*, 16, 63–72.
- Dorval, M., Patenaude, A. F., Schneider, K., Kieffer, S. A., DiGianni, L., Kalkbrenner, K., Bromberg, J. I., Basili, L. A., Calzone, K., Stopfer, J., Weber, B. L., & Garber, J. E. (2000). Anticipated versus actual emotional reactions to disclosure of results of genetic tests for cancer susceptibility: Findings from *p53* and *BRCA1* testing programs. *Journal of Clinical Oncology*, 18, 2135–2142.
- Dudok de Wit, A., Tibben, A., Frets, P., Meijers-Heijboer, E., Devilee, P., Klijn, J., Oosterwijk, J., & Niermeijer, M. (1997). *BRCA1* in the family: A case description of the psychological implications. *American Journal of Medical Genetics*, 71, 63–71.
- Easton, D. F., Bishop, D. T., Ford, D., Crockford, G. P., & the Breast Cancer Linkage Consortium. (1993). Genetic linkage analysis in familial breast and ovarian cancer: Results from 214 families. *American Journal of Human Genetics*, 52, 678–701.
- Eisen, A., & Weber, B. L. (1999). Prophylactic mastectomy: The price of fear. *New England Journal of Medicine*, 340, 137–138.
- Eisen, A., & Weber, B. L. (2001). Prophylactic mastectomy for women with *BRCA1* and *BRCA2* mutations: Facts and controversy. *New England Journal of Medicine*, 345, 207–208.
- Evans, D. G., Burnell, L. D., Hopwood, P., & Howell, A. (1993). Perception of risk in women with a family history of breast cancer. *British Journal of Cancer*, 67, 612–614.
- Evans, W., & Relling, M. V. (1999, October 15). Pharmacogenetics: Translating functional genomics into rational therapeutics. *Science*, 286, 487–491.
- Faraone, S. V., Tsuang, M. T., & Tsuang, D. W. (1999). *Genetics of mental disorders: A guide for students, clinicians, and researchers*. New York: Guilford Press.
- Foster, M. W., Eisenbraun, A. J., & Carter, T. H. (1997–1998). Genetic screening of targeted subpopulations: The role of communal discourse in evaluating sociocultural implications. *Genetic Testing*, 1, 269–274.
- Glanz, K., Grove, J., Lerman, C., Gotay, C., & LeMarchand, L. (1999). Correlates of intentions to obtain genetic counseling and colorectal cancer gene testing among at-risk relatives from three ethnic groups. *Cancer Epidemiology, Biomarkers, and Prevention*, 8, 329–336.
- Gould, R. L. (1997). *Cancer and genetics: Answering your patients' questions*. Huntington, NY: PRR.
- Harper, P. S., Lim, C., & Craufurd, D. (2000). Ten years of presymptomatic testing for Huntington's disease: The experience of the U.K. Huntington's Disease Prediction Consortium. *Journal of Medical Genetics*, 37, 567–571.
- Hartmann, L. C., Schaid, D. J., Woods, J. E., Crotty, T. P., Myers, J. L., Arnold, P. G., Petty, P. M., Sellers, T. A., Johnson, J. L., McDonnell, S. K., Frost, M. H., & Jenkins, R. B. (1999). Efficacy of bilateral prophylactic mastectomy in women with a family history of breast cancer. *New England Journal of Medicine*, 340, 77–84.
- Hopwood, P. (1997). Psychological issues in cancer genetics: Current research and future priorities. *Patient Education and Counseling*, 32, 19–31.
- International Human Genome Sequencing Consortium. (2001, February 15). Initial sequencing and analysis of the human genome. *Nature*, 409, 860–921.
- Jacobs, L. A., & Deatrick, J. A. (1999). The individual, the family, and genetic testing. *Journal of Professional Nursing*, 15, 313–324.
- Jeffords, J. M., & Daschle, T. (2001, February 16). Policy issues: Political issues in the genome era. *Science*, 291, 1249–1251.
- Jenkins, J., Blitzer, M., Boehm, K., Feetham, S., Gettig, E., Johnson, A., Lapham, V., Patenaude, A. F., Reynolds, P., Guttmacher, A. E., & the Core Competency Working Group of the National Coalition for Health Professional Education in Genetics. (2001). Recommendations of core competencies in genetics essential for all health professionals. *Genetics in Medicine*, 3(2), 155–158.
- Juengst, E. T. (1995). The ethics of prediction: Genetic risk and the physician-patient relationship. *Genome Science and Technology*, 1, 21–36.
- Julian-Reynier, C., Eisinger, F., Vennin, P., Chabal, F., Aurran, Y., Nogues, C., Bignon, Y.-J., Machelard-Roumagnac, M., Maugeard-Lougoutin, C., Serin, D., Orsoni, P. L., & Sobol, H. (1996). Attitudes towards cancer predictive testing and transmission of information to the family. *Journal of Medical Genetics*, 33, 731–736.
- Kahneman, D., & Tversky, A. (1979). Prospect theory: An analysis of decision under risk. *Econometrica*, 47, 263–291.
- Klausner, R. D. (1998). Foreword. In K. Offit, *Clinical cancer genetics: Risk counseling and management* (pp. ix–x). New York: Wiley-Liss.
- Leavitt, B., Wellington, C. L., & Hayden, M. R. (1999). Recent insights into molecular pathogenesis of Huntington disease. *Seminars in Neurology*, 19, 385–395.
- Lerman, C. (2000, August 5). *Genetic influences on smoking behavior*. Paper presented at the 108th Annual Convention of the American Psychological Association, Washington, DC.
- Lerman, C., Daly, M., Masny, A., & Balshem, A. (1994). Attitudes about genetic testing for breast-ovarian cancer susceptibility. *Journal of Clinical Oncology*, 12, 843–850.
- Lerman, C., Hughes, C., Lemon, S. J., Durham, C., Narod, S., & Lynch, H. T. (1998). What you don't know can hurt you: Adverse psychologic effects in members of *BRCA1*-linked and *BRCA2*-linked families who decline genetic testing. *Journal of Clinical Oncology*, 16, 1650–1654.
- Lerman, C., Narod, S., Schulman, K., Hughes, C., Gomez-Camirero, A., Bonney, G., Gold, K., Trock, B., Main, D., Lynch, J., Fulmore, C.,

- Snyder, C., Lemon, S. J., Conway, T., Tonin, P. L., Lenoir, G., & Lynch, H. (1996). *BRCA1* testing in families with hereditary breast-ovarian cancer: A prospective study of patient decision-making and outcomes. *JAMA*, 275, 1885-1892.
- Lerman, C., Seay, J., Balslem, A., & Audrain, J. (1995). Interest in genetic testing among first-degree relatives of breast cancer patients. *American Journal of Medical Genetics*, 57, 385-392.
- Li, F. P. (1995). Identification and management of inherited cancer susceptibility. *Environmental Health Perspectives*, 103(Suppl. 8), 297-300.
- March, R. (2000). Pharmacogenetics: The genomics of drug response. *Yeast*, 17, 16-21.
- Marteau, T. M. (1999). Communicating genetic risk information. *British Medical Bulletin*, 55, 414-428.
- Marteau, T. M., & Croyle, R. T. (1998). Psychological responses to genetic testing. *British Medical Journal*, 316, 693-696.
- Massie, M. J., Mushkin, P., & Stewart, D. E. (1998). Psychotherapy with a woman at high risk for developing breast cancer. *General Hospital Psychiatry*, 20, 189-197.
- Meijers-Heijboer, H., van Geel, B., van Putten, W. L. J., Henzen-Logmans, S. C., Seynaeve, C., Menke-Pluymers, M. B. E., Bartels, C. C. M., Verhoog, L. C., van den Ouweland, A. M. W., Nierjeijer, M. F., Brekelmans, C. T. M., & Klijn, J. G. M. (2001). Breast cancer after prophylactic mastectomy in women with a *BRCA1* or *BRCA2* mutation. *New England Journal of Medicine*, 345, 159-164.
- Miller, S. M., Shoda, Y., & Hurley, K. (1996). Applying cognitive-social theory to health-protective behavior: Breast self-examination in cancer screening. *Psychological Bulletin*, 119, 70-94.
- Offit, K. (1998). *Clinical cancer genetics: Risk counseling and management*. New York: Wiley-Liss.
- Owen, M. J., & Cardno, A. G. (1999). Psychiatric genetics: Progress, problems, and potential. *Lancet*, 354(Suppl. 1), 11-14.
- Patenaude, A. F. (2001). Genetic testing and family relationships. In B. Sarason & S. Duck (Eds.), *Personal relationships: Implications for clinical and community psychology* (pp. 43-59). Chichester, England: Wiley.
- Petersen, A. (2001). Biofantasies: Genetics and medicine in the print media. *Social Science and Medicine*, 52, 1255-1268.
- Roberts, R. (2000). A perspective: The new millennium dawns on a new paradigm for cardiology—molecular genetics. *Journal of the American College of Cardiology*, 36, 661-667.
- Saunders, A. M. (2000). Apolipoprotein E and Alzheimer disease: An update on genetic and functional analyses. *Journal of Neuropathology and Experimental Neurology*, 59, 751-758.
- Smith, K. R., West, J. A., Croyle, R. T., & Botkin, J. R. (1999). Familial context of genetic testing for cancer susceptibility: Moderating effect of siblings' test results on psychological distress one to two weeks after *BRCA1* mutation testing. *Cancer Epidemiology, Biomarkers, and Prevention*, 8, 385-392.
- Struewing, J. P., Hartge, P., Wacholder, S., Baker, S. M., Berlin, M., McAdams, M., Timmerman, M. M., Brody, L. C., & Tucker, M. A. (1997). The risk of cancer associated with specific mutations of *BRCA1* and *BRCA2* among Ashkenazi Jews. *New England Journal of Medicine*, 336, 1401-1408.
- Weitzel, J. N. (1999). The current social, political, and medical role of genetic testing in familial breast and ovarian carcinomas. *Current Opinion in Obstetrics and Gynecology*, 11, 65-70.
- Wilfond, B. S., Rothenberg, K. H., Thomson, E. J., & Lerman, C. (1997). Cancer genetic susceptibility testing: Ethical and policy implications for future research and clinical practice. Cancer Genetic Studies Consortium, National Institutes of Health. *Journal of Law, Medicine, and Ethics*, 25, 252-255.
- Zhang, Y., Proenca, R., Maffei, M., Barone, M., Leopold, L., & Friedman, J. M. (1994, December 1). Positional cloning of the mouse obese gene and its human homologue. *Nature*, 372, 425-532.

ORDER FORM

Start my 2002 subscription to *American Psychologist!*

ISSN: 0003-066X

_____ \$198.00, INDIVIDUAL NONMEMBER _____
 _____ \$449.00, INSTITUTION _____
 In DC add 5.75% / In MD add 5% sales tax _____
TOTAL AMOUNT ENCLOSED \$ _____

Subscription orders must be prepaid. (Subscriptions are on a calendar basis only.) Allow 4-6 weeks for delivery of the first issue. Call for international subscription rates.



AMERICAN
PSYCHOLOGICAL
ASSOCIATION

SEND THIS ORDER FORM TO:
 American Psychological Association
 Subscriptions
 750 First Street, NE
 Washington, DC 20002-4242

Or call (800) 374-2721, fax (202) 336-5568.
 TDD/TTY (202) 336-6123.
 Email: subscriptions@apa.org

Send me a FREE Sample Issue

Check Enclosed (make payable to APA)

Charge my: VISA MasterCard American Express

Cardholder Name _____

Card No. _____ Exp. date _____

Signature (Required for Charge)

BILLING ADDRESS: _____

City _____ State _____ Zip _____

Daytime Phone _____

SHIP TO:

Name _____

Address _____

City _____ State _____ Zip _____

APA Member # _____ *AMPA12*