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Genetic Testing: A Modern Version of Pandora's Box?

As a teenager I vividly remember once visiting a zoo that had a wonderful collection of reptiles. A large exhibit of king cobras was separated from the viewer only by a piece of plate glass. Pasted on the bottom of the glass was a small sign that read, "Don't tap on the glass—what would you do if it broke?"

How many times during the recent explosion in the field of diagnostic technology have we all "tapped on the glass" only to find that we were unprepared and unable to manage the information that landed in our laps?

Whether we are physicians, nurses, or any other health care provider, we all want to obtain as much information about our patients as we can. When we know how to use that information, we perform a great service for our patients. When we don't, we run the risk of opening Pandora's box.

The fine line between the wonders of modern technology and the opening of Pandora's box is perhaps best illustrated in the area of genetic testing. Although the Human Genome Project is only a few years old, it has already produced much information about the 3 billion base pairs and 100,000 genes that make up our DNA pool.

At the same time, genetic research has identified fifteen genes implicated in familial malignancies. Enormous interest has been generated on this subject, given the fear of cancer in the general population and the public perception that cancer is hereditary. Not surprisingly, commercial companies are rushing to market the new technology and to make it available to patients and their families.

Patient interest in genetic screening is just beginning. Within a year or two we can expect increasing pressure from the public to offer testing, both in the physician's office and as part of cancer services in our hospitals. Anyone considering starting a genetic screening program should be aware of the many problems, both scientific and ethical, raised by such testing.

Although there are many legitimate questions about which populations should be screened, the real problems may begin when a positive test is found. Once the patient is known to be at high risk, a reasonable program must be outlined to reduce that risk. This means increased screening and testing, much of which may not be covered by standard insurance. For some genetic defects, such as familial adenomatous polyposis, the clinical syndrome is obvious at colonoscopy and the management (total colectomy) seems fairly clear. For most of the newly discovered disorders, however, the exact recommendations are less certain. This is certainly true for the more complex genetic defects such as BRCA-1 and hereditary nonpolyposis colon cancer (HNPCC) in which more than one organ may be the target of malignant change.

Genetic counseling is a required part of a genetics screening program. Trained counselors are difficult to find, and training programs are currently very limited. Incorrect advice to extremely anxious patients and relatives may be worse than no advice at all, particularly when the diagnosis of a genetic disorder may place the patient in jeopardy of losing his or her insurance or result in employment discrimination. Confidentiality is obviously very important, but can be difficult when entries must be made in medical records.

Persons from an affected family who test negative for the genetic defect also present a problem. These individuals may skip standard screening, believing that they are immune to normal cancer risks, and may even feel guilty that they have been spared the problems of their affected relatives.

For reasons such as these, both the National Advisory Council for Human Genome Research and the American Society of Human Genetics have recommended that genetic testing, even in high-risk families, remain investigational. To move this testing into the community setting with no clear plan for dealing with the information gained is clearly to tap hard on the glass of the cobra cage. Nevertheless, the information to be learned is potentially very valuable and must be made available as soon as possible.

The National Cancer Institute, under the leadership of Dr. Richard Klausner, is considering a program of national protocols available to a wide range of physicians in the community, and through them, to the community cancer centers. These protocols can provide information on interpreting tests, recommend appropriate counseling, and follow large numbers of patients to measure the success of the interventions. This approach would have the best of both worlds—early access by the community and scientific review by experts in the field.

ACCC will present a special symposium on this important topic at the 13th National Oncology Economics Conference this September. At this presentation, we will honor Dr. Henry Lynch, director of the Creighton University Cancer Center, with the Award for Outstanding Achievement in Clinical Research. Dr. Lynch is a leader in alerting the medical community to the hereditary basis of certain gastrointestinal, breast, and ovarian cancers. Please plan to join us!

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