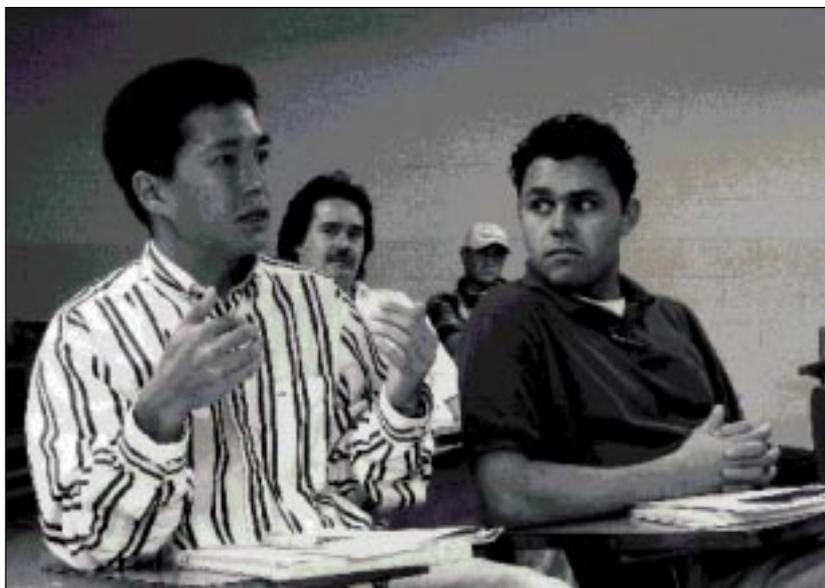

Social Issues and Genetic Testing: A Case Study Using Advocacy Groups

Student Forum Explores Potential Uses and Misuses of Genetic Information

Deborah Campero Clark

Many biologists regard the twentieth century as the "age of genetics." Certainly, it is a time of revolutionary discovery and technological advancement. Genetic testing, artificial insemination, and DNA fingerprinting have become commonplace and gene therapy promises to become so in the near future.

Controversies over the application of these techniques are now at the forefront of discussions, both in the popular media and in scientific circles. Genetics has escaped the laboratory and entered mainstream society. As a result, an understanding of genetic principles alone is no longer sufficient to evaluate this fast-developing field of biology. As pointed out by Dr. Howard Stein (1992), "Genetic knowledge does not occur in a social vacuum. The scientific account is neither the only story, nor the entire story."



The goal of the Middle Tennessee State University course is to provide students an opportunity to explore and express their own views about the use of genetic information.

I teach the introductory genetics course for majors at Middle Tennessee State University. As an introductory course taken in the sophomore year, emphasis is placed on general principles upon which more complex ideas are built. However, I feel that in addition to presenting the traditional material, it is important to expose students to bioethical issues, including the interface between genetics and society as well as the social responsibilities of

scientists. Recent studies confirm that students, as well as educators, believe that bioethics education is an important component of science instruction and should be a part of the science classroom (Bisbee, 1994; Downie, 1993; Kormondy, 1990).

In my genetics course, I have successfully utilized a discussion forum that allows students to explore a plexus of viewpoints concerning the promise and potential dangers of genetic technology. Specifically, students examine the

ethical, social, and legal problems that arise from the ability to detect, and in some cases correct, genetic defects. The discussion format provides an excellent means of achieving interdisciplinary objectives in a science course.

Deborah Campero Clark is an assistant professor in the department of biology, Middle Tennessee State University, Box X120, Murfreesboro, TN 37132; e-mail: dclark@frank.mtsu.edu

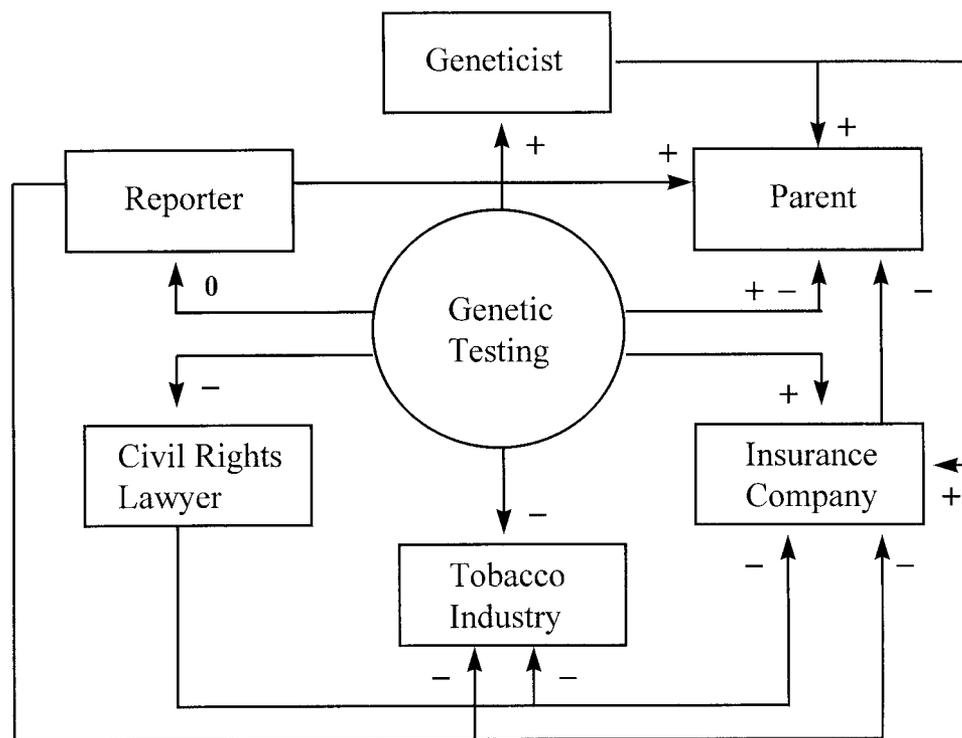


Figure 1: Diagrammatic representation of the potential relationships among discussion participants. Each subgroup of the population is differentially affected by the development of a test for the ismoky allele and the use of test information by other groups

GENETIC TESTING

Genetic testing is an excellent topic for discussion in introductory biology courses for several reasons. *First*, the potential uses and misuses of genetic information are currently being debated by prominent scientists (Hubbard and Lewontin, 1996). This debate has extended into the popular press. Numerous articles about genetic testing have appeared in publications ranging from U. S. *News and World Report* and *Forbes* to recent issues of local and national newspapers. *Second*, this issue has far-reaching ethical, social, and legal implications. Concern focuses on the use of genetic information and the protection of genetic privacy. Questions about who should be tested and who should have access to test results are, as yet, unresolved. In addition to the Ethical, Legal, and Social Implications (ELSI) branch of the Human Genome Project, numerous private "task forces" have been established to examine ethical issues related to genetic testing (Benowitz, 1996).

Finally, most, if not all, students will be confronted with the issues surrounding genetic testing, either as a parent requesting prenatal diagnostic testing or as a patient seeking information about disease susceptibility. Discussions of the utility of genetic testing are timely and will become increasingly important in the future.

GOALS

My goal is to provide students an opportunity to explore their own views about the use of genetic information. A forum is provided for a structured discussion that centers on a hypothetical scientific study and its social implications. Students evaluate the scientific rigor of the study and determine how the data obtained by a hypothetical research team should be interpreted. After this phase is completed, students are challenged to consider how these data are used by different groups of individuals, such as scientists, insurance companies, employers, and prospective parents (see Figure 1). After complet-

ing this exercise, students should be able to:

- ▲ evaluate social issues involving genetics
- ▲ explore their own personal views about genetic topics
- ▲ evaluate current research and controversies in genetics

THE DISCUSSION FORMAT

I use smoking as the focus of the discussion. In the exercise, students are provided a hypothetical study purporting to show a genetic link to nicotine addiction. The discussion can also be centered around the genetic basis of drug use, alcoholism, or homosexuality. Any topic can be selected, but I think that the above examples are excellent choices because they do not represent an absolute "life or death" situation: the "socially correct" or "morally right" decision is not as clear in these situations. In addition, each of these behaviors is expected to be influenced by the environment as well as

genes. This additional facet of the problem challenges students to realize that genetic constitution is not the only factor responsible for an individual's behavior.

This exercise serves as the "capstone" in my genetics course. I provide students the instructions for this exercise four- to six-weeks prior to the discussion date. This exercise can be used at any time during the semester provided that the students have an understanding of basic genetic concepts including Mendelian genetics, pleiotropy and polygenic inheritance, and the tenets of the human genome project. I have used this exercise in the laboratory portion of my genetics course because of the time constraints imposed by a 50-minute lecture.

On the day of the discussion, I arrange the students in their respective groups (five students per group) and allow them to discuss, within each group, how they approached their assigned position. Some of the groups have already met, on their own accord, outside of class and most of the students have discussed the topic with classmates prior to the discussion. Each group is asked to list the three major points they would like to make in defense of their position. If the group cannot agree, each faction is allowed to present its ideas. The discussion begins after all groups have outlined their positions. The class is usually eager to begin debating after they hear the first group's arguments. I serve as moderator, but I do ask questions.

The entire exercise can be completed in one laboratory session (my laboratories are scheduled to meet one hour and 50 minutes each week). My introductory remarks are usually brief and last no more than five minutes. I also provide the students five to 10 minutes to prepare their opening arguments. Approximately one hour is required for the students to present their arguments and to complete the discussion. This is sufficient time for the major points to be covered in detail by the students.

After the discussion has ended, I summarize the overall session and

compare the focus of the current discussion to those of previous classes. I also conduct an informal survey to assess the student's reactions to the topic and exercise. Summary remarks require 10 minutes. If the "60 Minutes" story on genetic confidentiality is shown (see follow-up exercises below), an additional 20 minutes should be scheduled. After the discussion, I require my students to submit a written defense of their assigned position for evaluation. I assign points based on the quality of the arguments presented.

INSTRUCTIONS TO STUDENTS

The following are instructions I give to the class at the outset of the exercise:

Several articles focusing on the ethical issues in human genetics are on reserve in the library. Each of these papers discusses the scientific and sociological problems associated with research in the field of genetics. They will provide you background information outlining the promise and potential dangers of genetic information. These issues will form the basis of a class discussion.

This exercise should be informative, but it should also be a fun experience. It is a chance to apply some of the knowledge you have gained this semester to "real-world" issues. It will also be an opportunity to interact with your classmates. The hope is that this discussion will open your eyes to one of the most prominent, current controversies in genetics and what is at stake.

The genetic "problem" that will be addressed in class is outlined below along with several different "points of



KENNETH ROBINSON, MIDDLE TENNESSEE STATE UNIVERSITY PHOTOGRAPHIC SERVICES

In a time of revolutionary discoveries and technological advances, Professor Clark encourages students to consider the social responsibilities of scientists.

view." Read over the problem and the various viewpoints presented. You should write a few brief statements in support of, and against, each point of view. Your instructor will assign you one position to examine in greater detail. You will be required to write a position paper on your assigned position. You will also be expected to vigorously defend this position in the class discussion. Be sure to read and consider all of the positions so you will be able to:

- ▲ defend and answer questions about your stance, and
- ▲ pose questions and arguments against the positions of others.

The Problem: Localization of a "Smoking Gene"

A team of scientists has located a gene they believe is responsible for a predisposition to tobacco use. They found this gene by examining the genome of 300 individuals who were attempting to stop smoking. The allele associated with tobacco use has been

named “smoky” by the team. Almost 59 percent of the smokers examined had the allele “smoky,” which led the researchers to conclude that it is probably associated with the addiction. However, no subdivision of the population was considered and a control group was not examined. The news media have reported that a “Smoker’s Gene” has been discovered, but the study has not been published in a scientific journal.

Position 1: The Genetic Expert

You are a geneticist, a leading authority in the development and implementation of genetic testing and screening programs. You should be prepared to explain how data on the “smoky” allele should be interpreted, what conclusions can be drawn from the study, and how this study will impact society. Be prepared to face criticism for the “sketchy” data obtained by the research team. You should become familiar with, and be prepared to discuss, the medical benefits of genetic testing.

Position 2: The Former Smoker Expecting a Child

You are a former smoker who is now expecting a child. Naturally, you are concerned that you may have passed your smoking problem on to your child. Discuss your reasoning behind a desire to have your child tested and why you want to know your child’s genetic make-up.

Position 3: The President of a Tobacco Company

You are the president of a tobacco company that makes millions of dollars each year from the sale of tobacco products. Your company has been named in several wrongful death lawsuits filed by the family members of individuals who died of lung cancer. Discuss why you would, or would not, support genetic testing for the “smoky” allele. Be sure to consider how this discovery will impact the company’s legal battles and future sales.

Position 4: The President of an Insurance Company



KENNETH ROBINSON

The discussion format of the exercise offers instructors an excellent means of achieving interdisciplinary objectives in a science course.

You are the president of a health/life insurance company that loses money each year treating the health-related problems of the tobacco users you insure. Discuss your stance on who should be tested and who should have access to the test results. Consider what your policy would be concerning those persons already insured as well as those seeking coverage with your company.

Position 5: The Civil Rights Lawyer

You are a civil rights lawyer. You are opposed to using genetic testing to determine the suitability of an individual for insurance coverage or employment. In short, you are opposed to any use of genetic test information outside of medical treatment. Defend your call for legislation to protect the genetic privacy of patients.

Position 6: The Newspaper Columnist

You are a columnist for a large, nationally distributed newspaper. You have been assigned to report on the “smoky” allele and its impact on health care. Describe how you will cover the story. How will you decide on the focus of the article you are writing? What will the headline read and what infor-

mation will you include in your article?

ARTICLES SELECTED FOR STUDENT EVALUATION

The literature focusing on genetic testing and the use of test information is vast. I provide students with several general focus articles as well as articles centering specifically on the assigned positions. The citations for the set of articles I recently provided to my students are listed by category below.

General:

- ▲ Brownlee, S. 1994. Tinkering with destiny. *U. S. News and World Report* August 22:59-67.
- ▲ Horgan, J. 1993. Eugenics revisited. *Scientific American* June:122-131.
- ▲ Rennie, J. 1994. Grading the gene tests. *Scientific American* June: 80-97.

The Genetic Expert:

- ▲ Hubbard, R., and R. C. Lewontin. 1996. Pitfalls of genetic testing. *New England Journal of Medicine* 334:1192-1193.

The Former Smoker:

- ▲ Genetic testing and gene therapy: What they mean to you and your family. *March of Dimes Birth Defects Foun-*

dation Brochure 1992.

▲ Wertz, D. C., J. N. Fanos, and P. R. Reilly. 1994. Genetic testing for children and adolescents: Who decides? *Journal of American Medical Association* 272:875-881.

The Tobacco Company Executive:

▲ Orentlicher, D. Genetic screening by employers. *Journal of American Medical Association* 263:1005, 1008.

The Insurance Company President:

▲ Pokorski, Robert J. 1995. Genetic information and life insurance. *Nature* 376:13-14.

The Civil Rights Lawyer:

▲ Lewin, D. I. 1995. DNA dogtags? Don't tell it to the marines. *The Journal of NIH Research* July.

▲ Summary of *The Genetics Confidentiality and Nondiscrimination Act of 1996*.

FOLLOW-UP EXERCISES

After the discussion, I ask students to further investigate the question of genetic testing by examining opinions of the "experts." The newsmagazine "60 Minutes" recently aired a story addressing some of the issues we examine in this exercise. By coincidence, our last class discussion occurred during the same week this story aired. Many of my students watched the episode specifically to compare the views of the "experts" with those of their classmates.

Much to their surprise, our class discussion focused on the same problems and issues identified by the individuals interviewed in the "60 Minutes" story. I plan to show this episode after future class discussions. A second follow-up exercise challenges the students to search the primary literature for any studies linking smoking and genetics. Students are encouraged to take advantage of the plethora of subject matter available on the World Wide Web.

PERSONAL OBSERVATIONS

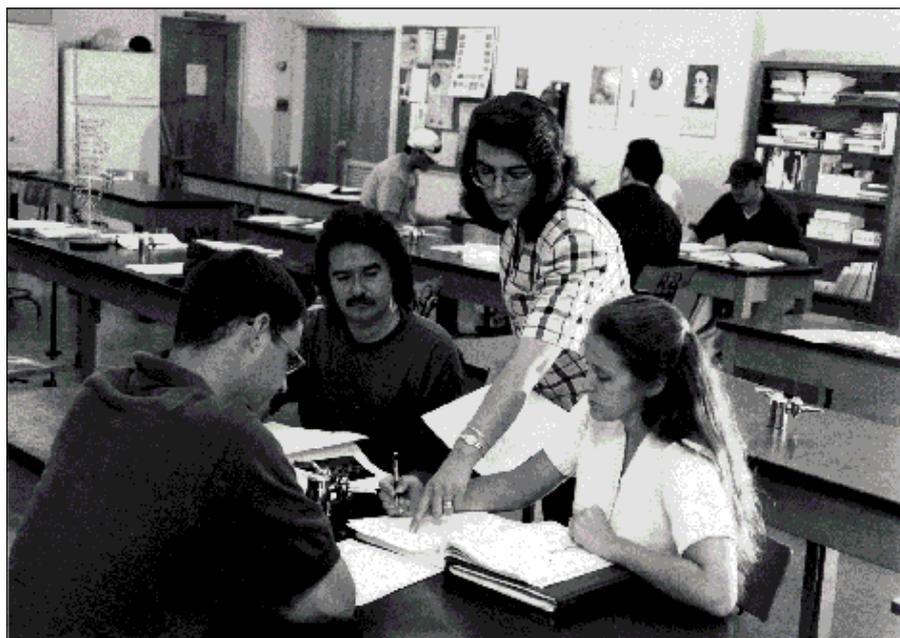
I have used this exercise in five different sections of genetics: three

sections evaluated the discovery of an allele predisposing an individual to drug use (the allele "high") while the remaining two sections considered the smoking allele "smoky." In each case, classroom discussions were lively, intelligent, and thought-provoking. As planned, each class focused on a different aspect of the study: some criticized the rigor of the scientific data, while other classes focused on the use of the information

"I love the debate thing. Definitely a must for next semester."

* * *

The success and popularity of this exercise have led to the development of a new course (*Social Issues and Genetic Technology*) focusing specifically on the social aspects of genetic technology. This course will afford students the opportunity to closely evaluate the many social and ethical questions surrounding the "new genetics." □



The debate exercise is a chance for students to apply some of the knowledge they have gained over the semester to "real-world" issues and to interact with classmates.

obtained in the study. In several cases, the discussion carried on even after the class ended.

While I have not evaluated this exercise specifically, some of my students felt strongly enough to discuss the exercise with me and to provide comments in their written course evaluations. The one negative comment in reference to this assignment was "I did not care for the discussion group." Positive comments included:

"The genetics position paper was also a great aid because I had to apply what I had learned in class to my paper. The articles were very interesting."

"I especially enjoyed the discussion group we did. It provided a chance for us to voice our opinions and work together."

Acknowledgements

The author would like to especially thank J. Wagner (Transylvania University) for generously supplying the format for this discussion. P. Mathis, J. Du Bois, and S. Swain (Middle Tennessee State University), and S. DeBano (University of Kentucky) provided comments that greatly improved an earlier draft of this manuscript.

References

- Benowitz, S. 1996. Scientists struggling with concerns raised by genome project progress. *The Scientist* 10:1, 6-7.
- Bisbee, L. A. 1994. Ethics in the science classroom. *Journal of College Science Teaching* 24:132-134.
- Downie, R. 1993. The teaching of bioethics in higher education of biologists. *Journal of Biological Education* 27:34-38.
- Hubbard, R. and R. C. Lewontin. 1996. Pitfalls of genetic testing. *New England Journal of Medicine* 334:1192-1193
- Kormondy, E. J. 1990. Ethics and values in the biology classroom. *The American Biology Teacher* 52:403-407.
- Stein, Howard F. 1992. The human genome as metaphor. *Journal of Family Practice* 35:256-258