Exploring Bioethical Choices

At HHMI's 2003 Holiday Lectures, students use improvisational play to confront tough issues.

Three genetic counselors, two lawyers, a married couple, their blind daughter, their normal son, and their unborn child (yes, their unborn child) take their places on the auditorium stage at HHMI headquarters in Chevy Chase, Maryland. Until this moment, the actors had been Washington, D.C.-area high school students attending the Institute's 11th annual Holiday Lectures on Science, in December 2003. Now, having volunteered to play roles in an improvised dramatization of ethical issues raised by genetic testing and counseling, they are wrestling with some of the thorny problems that accompany the miracles of modern biology.

The role-playing complements lessons learned from four lectures by HHMI investigators Bert Vogelstein from the Sidney Kimmel Comprehensive Cancer Center at the Johns Hopkins University School of Medicine, and Huda Y. Zoghbi at the Baylor College of Medicine. Their topic: "Learning from Patients: The Science of Medicine."

In the scenario developed by Vogelstein and Zoghbi, a mother and father have two children: a 3-year-old girl with retinoblastoma (a rare eye cancer that is usually inherited) and a 12-year-old boy who does not. The father's mother also had retinoblastoma, the only treatment for which is removal of the eyes. Half of all offspring of a parent with the retinoblastoma mutation will also carry it, and 9 out of 10 of those will develop the disease.

Now expecting another child, the couple seeks advice from genetic counselors. "What are the chances that this baby will have retinoblastoma?" they ask. "Should we even have it?"

In the spirited discussion that follows, the students on stage and their classmates in the audience explore what genetic counselors can and should advise. For example, when a counselor tells the couple what they "should" do, one of the lawyers pops up shouting "lawsuit, lawsuit." The role of counselors is to educate, not instruct, Zoghbi explains.

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Investigators, a bioethicist, and high school students wrestle with some of the tough questions raised by genetic testing and counseling.

The role-play includes a frank discussion of abortion issues. "I think you should have me," says the fetus. "Even if I'm disabled, who's to say that my life is not worth living?" And when the mother describes her blind daughter as "a burden," the girl protests. "I aspire to be a Braille teacher for blind children in underdeveloped countries," she says. "I am a gift from God, both a burden and a blessing."

"What if we had the skill to fix this gene?" asks Laurie Zoloth, a Northwestern University bioethicist who chairs HHMI's bioethics advisory board. "Should we do it?"

Caution prevails. "If you start changing one gene, it might set a precedent," one of the genetic counselors remarks. A student in the audience calls it "like going online and ordering a child." Another comments, "Evolution is based on genetic diversity for a reason."

The role-playing students confront a final twist in the tale. The counselors recommend that the father be tested for the retinoblastoma mutation. He doesn't have it. The baby is born, and she develops retinoblastoma. So the mother is tested. She doesn't carry the mutation either.

"How could this be?" Vogelstein asks the audience. "The 'father' isn't the father of the child," several students suggest. "Exactly," says Vogelstein. "Genetic counselors, what are you going to do now? Should the mother be asked to identify the baby's father? Should he be told? If so, by whom? Should the mother's husband be told?"

In real genetic counseling, "this does happen," Zoloth tells the students. Geneticists have learned to discreetly probe the medical and social history if a person presumed to be an "obligate carrier" (an individual who must carry a gene mutation based on analysis of family history) does not show signs of the disease in question, even though statistics show, for example, that some 90 percent of people with the mutation would be expected to exhibit symptoms.

"We know a lot more than we used to know, a lot less than we want to know, and we can't do as much as we'd like with the information we do have," says Zoloth.

Vogelstein points out that 15 years ago "this whole conversation would have been deemed science fiction. Today, we can test—and tell with certainty—whether someone does or does not carry a specific genetic mutation. That's the science. Now we are faced with the ethical choices."

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