

DNA Dilemmas

Readers and 'experts' weigh in on biomedical ethics

By KATHY A. FACKELMANN

"Beyond the Genome" outlined four real-life ethical dilemmas presented last summer at the Short Course in Medical and Experimental Mammalian Genetics held at the Jackson Laboratory in Bar Harbor, Maine (SN: 11/5/94, p.298). We asked SCIENCE NEWS readers to ponder those cases, described below, and tell us what they would do.

Here, we attempt to convey the flavor of those responses as well as explore what ethicists, geneticists, and genetic counselors think about the same four cases. The wide range of opinions offered by readers and the "experts" highlights the complex nature of such situations.

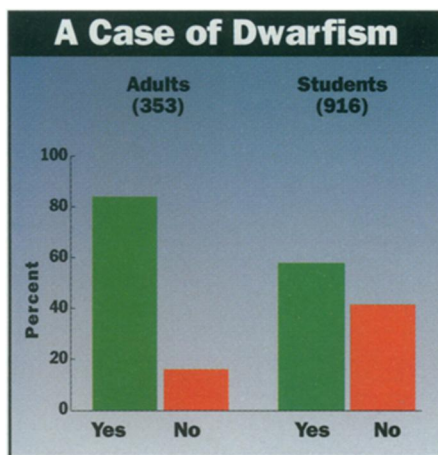
The experts say that in sorting through ethical dilemmas, they rely on certain principles:

- Autonomy — being free to make decisions involving one's own or a family member's health and well-being.
- Beneficence — doing the right thing; providing or promoting well-being and preventing harm.
- Justice — being fair.
- Nonmaleficence — doing no harm; acting with no harmful or selfish motives toward another person or society.
- Veracity — telling the truth.
- Fidelity — keeping all contracts and promises.

Ideally, these ethical principles operate in harmony. In real life, they can clash dramatically. Experts say they struggle with such cases. When principles conflict, a counselor may try to balance and weigh each obligation. Sometimes that process reveals a clear course of action. Other times, the moral waters remain murky.

Unlike other disciplines, where data may point to a definitive answer, a tricky case of ethics can become mired in conflicting values, emotions, and legal issues. Even the experts say there are cases in which there is no "right" answer.

Indeed, ethics is taught through the study of knotty examples like the four cases in the Nov. 5 SCIENCE NEWS. DNA testing affects nearly everyone, and the experts believe it is extremely important to develop the skills needed to find our way through such dilemmas.



In this case, a couple who both have achondroplasia, an inherited form of dwarfism, desire a dwarf child. They tell the genetic counselor they will abort a fetus destined to grow to normal height. Should the center perform the test, knowing the couple's intent?

This case revealed a difference between adult and student respondents (see sidebar, p.410). Of the adults who answered this query, 84 percent said the center should perform the test for this couple. The students split more evenly: 59 percent said they would okay the test; 41 percent would veto it.

Many readers believe only the couple should make such a personal decision. This view reflects the principle of autonomy.

Ann S. Pellegrino of Indiana says, "the job of the center is to provide the couple with the information they request, not to judge the morality of how the couple will use that information." She continues, "healthy fetuses are aborted every day in this country by couples who feel, for whatever reason, that they will not be able to raise the child properly."

Ray N. Franklin III of Colorado says, "when the issue comes down to a choice of abortion or pregnancy, the choice is solely the woman's and is intensely personal."

Other readers felt the center should refuse to do the test. Many thought the principle of doing no harm outweighed the couple's right to make the decision

to bear only a child with achondroplasia.

A Massachusetts high school student writes, "there's a chance the child might be ridiculed or not treated nicely by other kids." Robert C. Colgrove, also of Massachusetts, adds, "it should not be the job of a professional caregiver to help impose a genetic disease upon another human being."

Several readers thought the couple's desire to select a dwarf fetus smacked of eugenics. California reader Don Coolidge says, "I find the parents' wish ethically abhorrent and in no way different from the Chinese practice of aborting females."

Here's what the experts say.

Arthur L. Caplan, director of the Center for Bioethics at the University of Pennsylvania School of Medicine in Philadelphia, argues against the couple's request. Knowing the parents intend to abort a healthy fetus runs counter to the mission of detecting disease-causing genetic defects. "There's nothing wrong with the fetus," he says, "and so you don't want to be involved in ending pregnancies for reasons that have nothing to do with your medical skills."

Although some dwarfs don't regard their condition as a disability, Caplan rejects that view: "I think that is simply inconsistent with medicine's view." He likens the dwarf couple's request to the practice of aborting a healthy fetus simply because it is the "wrong" sex.

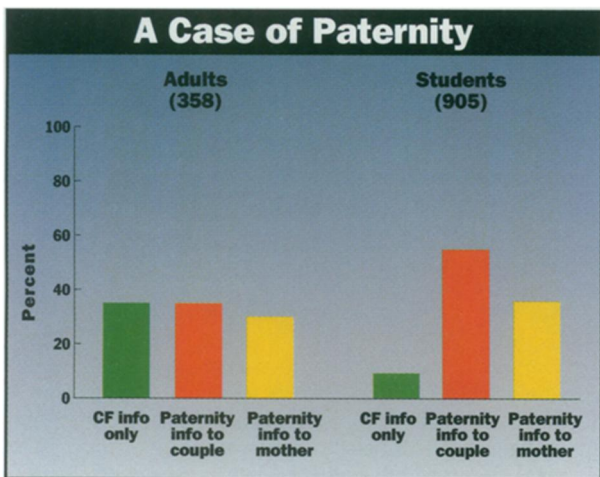
Ethicist Alexander M. Capron of the Law Center of the University of Southern California in Los Angeles points out that by deciding to carry to term only a fetus destined to be a dwarf, the couple will expose their future child to "serious physical as well as social burdens." He adds that "while a woman has a right under *Roe v. Wade* to abort for whatever reasons convince her, physicians are under no obligation to supply information simply because a client wants it."

"An abortion of a healthy fetus because it is healthy is very difficult to justify morally," adds Thomas H. Murray, director of the Center for Biomedical Ethics at Case Western Reserve University in Cleveland. "I would urge the genetic counselor not to collaborate with the couple."

The geneticists and genetic counselors, who work daily with patients, tend to take a very different view, one that relies on the concept of nondirective counseling.

Genetic counselor Rosalie A. Goldberg of the Montefiore Medical Center in New York City points to the code of ethics adopted in 1991 by the National Society of Genetic Counselors in Wallingford, Pa. Those guidelines say counselors should respect their clients' beliefs and feelings and allow them to make independent decisions, a crucial aspect of nondirective counseling.

Geneticist Eugene Pergament of Northwestern University Medical School in Chicago agrees. The dwarf couple may feel it would be psychologically difficult to raise a normal-size child, he points out. The counselor and geneticist shouldn't let their personal feelings interfere with the couple's choice, he adds.



In this case, a couple who already have a child with cystic fibrosis (CF) seek genetic counseling. They want to know their risk of having another CF child. The tests show that the husband is not the biological father of the child.

Who should be told? Of the adult readers who responded, 35 percent believed the counselor should explain the low risk of having another child with CF without mentioning the paternity issue. A subset added that if the couple asked for more details, they should be told that the husband was not the biological father. Another 35 percent believed the counselor should tell the couple about the paternity data, though some suggested that the mother be told separately first. And 30 percent of adult readers thought the counselor should relay the paternity findings to the mother only.

Of the students who answered this query, 9 percent would reveal only the CF risk; 56 percent would tell the couple that the husband was not the biological dad, with a large number opting to tell the mother first; and 35 percent would tell only the mother the paternity results.

Student readers seemed more concerned than adults that the biological

father be told he carries the CF gene: 71 percent of students and 52 percent of adult respondents want him to know.

Readers who voted against telling both husband and wife often turned to the principle of beneficence in their decision-making process.

A high school student in Oregon writes, "I think the counselor should tell only the mother. It's not the center's business if she wants to tell the husband or not, and telling the couple outright might be worse for the family." Knowledge of the paternity situation could harm the couple's marriage, an outcome that could hurt the child, the student adds.

Geoff Rieser of North Carolina offers a different viewpoint. He favors telling the couple that their future risk of producing another CF child appears minimal. The couple asked the center "only to give information about the odds of producing affected children," he says. "Additional information (such as paternity) is extraneous...."

Many respondents who would tell the couple of the paternity findings expressed a sense of justice as part of their reasoning. "The firm owes the clients all of the available information," writes Jacqueline McManus of Louisiana. "They contracted for the tests and are entitled to the results."

Ohio reader Wolf Roder says, "it seems to me, once the parents have a child with CF, they already know they are both carriers.... Why, then, did they go ahead with DNA testing? Clearly, only because they both already had reason to suspect the husband might not be the father. Instead of making assumptions, the lab can thus safely go ahead and tell the couple the truth."

And now for the expert opinion, which appears as diverse as the readers'.

"On this one, I would not reveal the information," Caplan says. "I'd duck and dodge and weave and try to get out of it. I think that lying might even be in order here." The counselor can give the couple their odds of CF without revealing paternity. To tell them about the paternity findings is "just asking for trouble," he says.

Goldberg would tell the mother privately that her husband is not the CF child's biological father. She wouldn't tell the husband for fear of harming the marriage and the child. "Do nothing to damage the relationship," she says.

Pergament would talk to the mother first and try to convince her to tell the husband. If she refused, he would find some way to inform the husband. "I don't see how you can walk away from the obligation of telling this man of the paternity findings," he says.

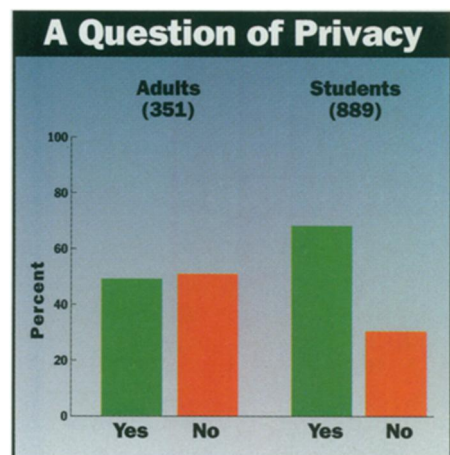
As for telling the biological father,

Judith G. Hall of the University of British Columbia in Vancouver, one of the organizers of the Bar Harbor ethics discussion, says the clinic has no contract with this man. The mother, however, does have a "social contract" with him.

Hall says many clinics have encountered such paternity cases. Her clinic now tells prospective patients that paternity can be determined through DNA testing and asks them how they want the situation handled — if it arises.

"We learned the hard way," Hall says.

Murray urges all genetic testing clinics to adopt a policy on paternity findings. "This is a situation you can and should avoid," he says.



In this case, doctors have just diagnosed a 30-year-old woman with familial adenomatous polyposis, an inherited disorder that carries an extremely high risk of colon cancer. The mutant gene underlying the disorder can cause a fatal case at a very early age. The counselor knows the bad gene may put the woman's children and her siblings at risk. Yet the woman refuses to tell her family or allow the children to be tested. What to do?

Again, adult readers split fairly evenly on this question. Forty-nine percent thought the genetic counselor should tell the patient's family. A few believed a counselor could inform the clan without revealing the patient's own results. Of the 51 percent who felt the clinic should not notify the relatives, many believed that the woman should be counseled to tell the family on her own.

The student responses showed a more definite trend to warn the relatives: 69 percent said the family should be informed, while 31 percent said don't overrule this woman's decision. Almost half of the latter group would counsel the woman to tell her family.

Many readers raised the concept of beneficence in their solutions.

Anna DelPrato of Massachusetts writes, "I was astonished and outraged that there should be any doubt as to whether or not the woman's family should be told that they may be carrying a harmful gene."

A Georgia high school student says, "I don't see how the counselor could just stand by and watch these unsuspecting relatives careen down a path toward a horrible death any more than I could watch a runaway train hurtling toward a kindergarten playground and not shout out a warning."

A college student from Louisiana urges the counselor to tell the rest of the family. The patient is "placing her entire family at risk of death just to protect her pride or job." This student, who is 18, says he speaks from experience: "I have familial adenomatous polyposis."

Yet some readers believe the right of confidentiality remains paramount.

A Michigan college student writes, "a patient's right to privacy has to be honored, even if family members are at risk."

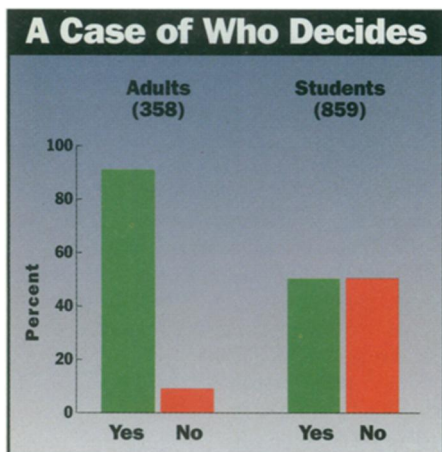
Says Kathleen M. Vyborny of Illinois, "the woman's information does not point to any identifiable victim, and there is no near certainty that any disease will immediately develop." Eileen Roy of California adds that "the family is perfectly able to seek testing on their own behalf if they desire it."

On this case, the experts agreed: All would warn the family.

This troubling case pits the woman's wish to keep her diagnosis private against her family's right to know of their legacy, Pergament says. "As important as confidentiality is, it is not as important as a person's life." He would counsel the woman extensively about the need to tell the family. If she still wouldn't, Pergament would try to find a way to notify the relatives without violating the contract with the woman.

"This patient has a moral obligation to tell her relatives," Murray adds. If the woman still refused after counseling, Murray says her physician would be justified in notifying the family of its risk.

Caplan would also override privacy concerns in this situation. "I think there is a duty to warn if you can prevent a real harm from befalling somebody else."



In this case, a pregnant woman worries about her family history of fragile X syndrome, an inherited form of mental

retardation. She tells the counselor she intends to abort if the fetus is a carrier of the trait and thus likely to be healthy but capable of passing the defective gene to the next generation.

The question: Should the test be done, given the patient's stated intent to abort an otherwise healthy fetus?

An overwhelming 91 percent of adult respondents said do the test — this woman (and every woman) has the right to abort a healthy carrier.

Students, however, split 50:50 on this question. Many students who opposed the woman's decision took issue with her right to make a future daughter's decision for her.

In addition, says one Georgia high school student, "this woman knew beforehand about her family's history of mental retardation and should have considered this before getting pregnant."

Yet many adult readers applauded the woman's decision.

"This is a perfect example of how applied genetics can benefit society," says William M. Coulter of Pennsylvania. "By making this decision, the woman takes steps to remove a harmful gene from the pool, increasing her chance of having a healthy child and improving the overall health of society." Frederick E. Mangelsdorf of New York says, "a fine and noble woman this is, worrying about the future. . . . Do what she wants."

"This case is on the frontier of how we define health," says Californian Richard H. Tew. "Appearing healthy can no longer by itself define 'healthy.' The woman's decision to abort even a carrier heralds what will be the norm in not many years."

Now for the expert opinion. "Legally, she has the right," points out

Murray, but he adds that the choice flirts with eugenics. "This one leaves me feeling very uneasy."

Caplan says that, unlike the dwarf parents, this woman seeks to abort a fetus carrying a known genetic flaw. He would offer her extensive counseling, yet if she held firm in her decision to abort, he would go along with it. Fragile X is a serious genetic disorder, one that causes much harm in the families who carry the gene for it, he points out.

Capron says, "although many people might reach the opposite conclusion, it does not seem unreasonable for a woman with the [fragile X] gene to want to avoid 'burdening' her daughter with the same moral dilemma."

It's not the counselor's place to override this woman's decision, Pergament says. "I'm not sure I'm willing to begin that slippery slope of telling her what to do," he says. "I would give her the information."

Many readers question the direction DNA testing may be taking. "I feel that we have begun to use genetic testing for purposes other than what it was originally intended for," writes Robert M. Heun of Massachusetts. A Virginia high school student concurs: "The health of a fetus should be the dominant concern. Not the personal [desires] of the parents."

Heun and others also worry that the selection of fetuses may backfire, "decreasing the variations necessary to allow our species to survive."

At the same time, says Jim Comstock of Texas, "let us ponder ethics and morality all we wish, but let us not shut the door to discovery." □

Notes from town hall

A surprising number of people replied to "Beyond the Genome." Early Monday, Nov. 7, the fax line at SCIENCE NEWS began ringing with the first few responses. They continued to pour in by fax and mail. By the Nov. 28 deadline, 1,942 letters had arrived: 498 from adult readers and 1,444 from students.

Clearly, the ethical decisions outlined in that story touched a chord in folks all over the United States and abroad. We heard from businesspeople, lawyers, scientists, teachers, doctors, nurses, musicians, and a convicted murderer; people with genetic diseases and their families and friends; church, work, family, and school groups, as well as individuals. SCIENCE NEWS received so many well-written, thoughtful rejoinders that it was just not possible to quote from each of them.

The purpose of this two-part series was not to conduct a scientific survey — our respondents were not randomly selected — but to stimulate a "town hall"

discussion. And in that, thanks to our readers, we succeeded. Most adults responded to all four cases; many students picked one or two. The adults wrote us spontaneously; most, but not all, students did so as part of a class assignment. Our gratitude to everyone who took the time to put their thoughts on paper.

Special thanks go to the 52 high school, college, graduate school, and other teachers who used our Nov. 5 article to spur classroom discussion of biomedical ethics. Elaine Schnitter of Irvine (Calif.) High School said, "my students are acutely aware of the implications of genetic testing, and I appreciate this opportunity to make known their attitudes and feelings."

And to the 1,444 students who responded: A new world is upon us. By grappling with these cases — and the issues they raise — in the thoughtful way you did, you have contributed to the national debate. — The Editors