

Introduction

Mary Shelley's famous novel, *Frankenstein*, is among the first literary responses to genetic engineering – humans tinkering with the mechanisms of human creation. The theme carries straight through to the Ridley Scott classic science-fiction film, "Blade Runner." In both stories human arrogance and hubris create powerful and dangerous creatures that become their creator's worst nightmare. The film "Gattaca" gives an indication of what a society of genetically engineered citizens could be like. Movies and stories like these can make us think that genetic science takes us into areas of scientific experimentation that we are not meant to explore and that cannot be controlled.

In this session we will consider the extent, given our genetic knowledge and power, to which we should regulate decisions that could affect future generations and perhaps even human nature itself. James Watson who, along with Francis Crick, is credited with discovering the overall structure of DNA, believes that genetic engineering is inevitable and a good thing, since nature, left to its own devices, can make some pretty horrendous mistakes from time to time. He calls our current method of reproduction "roulette," which implies that anyone who does not take advantage of the new technologies is simply foolish. What do you think? The case studies that follow take us quickly to the heart of the controversy.



An illustration of the double helix structure of DNA. It looks like a twisted ladder.

Scenario 1

Question to Think About

What are the ethical boundaries for genetic testing?

Eugenics is the science of improving the quality of human beings through interventions in the processes of reproduction. There are two types of eugenics: positive and negative. Negative eugenics involves the selective destruction of unwanted embryos or fetuses based on one or more of their genetic traits. Positive eugenics involves actual modifications to the embryo, which are intended to change the resulting human being for the better, either by eliminating an unwanted disorder or disease or by enhancing some capacity in the future person, such as greater height, intelligence, athletic ability, and so on. The first narrative considers negative eugenics, but with an unusual twist.

Narrative: Genetic Testing and Disability

You have been the pastor for a deaf couple, Roger and Sally, for three years. You are fortunate to have someone who knows sign language on your staff. Sally has just found out she is pregnant. They are happy but are concerned about the likelihood that their child will be deaf also. You have just attended a conference on genetic testing and know that there are tests that screen for many genetic disorders that cause deafness. You tell Roger and Sally about this option and give them a business card of a clinic that can do the screening. As they

Review Inherited Disease and Genetic Testing to refresh your memory on testing for predispositions for different diseases and the implications of knowing whether an embryo, fetus, infant, or adult might have inherited a gene that may increase the risk of the associated disease.

As they tell you their story you suddenly realize that they were not worried about having a deaf child, but a hearing child. They want to screen for and abort any fetus that will be able to hear.

Discussion Questions

- 1) Would your response have been different if Roger and Sally were blind? Why or why not?
- 2) What implied message does permitting selective abortions give to disabled people? A blind bioethicist, Adrienne Asch, argues that all prenatal screenings should be banned based largely on this implied message. (Compare this question with Session 2, Scenario 2, which raises similar ethical questions.)
- 3) We often use words like *disease*, *disorder*, *condition*, *disability*, and *trait* when referring to different sorts of bodily features. Is deafness a disease? A disorder? A condition? A disability? A trait? What are the different messages suggested by these terms?
- 4) If people are allowed to selectively abort embryos or fetuses to ensure a "healthy" child, does this imply that people should also be allowed to selectively abort to ensure having a "disabled" child? Is the principle the same? What is the principle used in the defence of selective abortions of any type?
- 5) The more control people have over reproductive outcomes the more significant the questions become concerning the rights of the person most affected by these decisions. Should there be rules established to regulate selective abortion based on a single trait or a set of traits?

Scenario 2

Question to Think About

*What does your faith tell you about the procedure
Bob and Carol are thinking about using?*

This scenario proceeds on several assumptions:

- that IVF is morally acceptable
- that selection of apparently healthy embryos from a raft of embryos is morally acceptable
- that sex selection is up to the parents.

Carol is concerned about genetic enhancement, which raises further ethical questions. How would you respond to these different layers of morality?

Narrative: Genetic Testing and Disability

You are a genetic counselor who works with members of faith communities. Bob and Carol are married athletes who have decided to have a child and are using IVF procedures to screen embryos for various genetic disorders. After selecting a few



embryos that seem relatively free from potentially harmful alleles they finally decide on a female. They name her Sarah.

The clinic representative then gives Bob and Carol a brochure on the “Gold Medal” program, a method for genetically modifying the selected embryo to give them the “Gold Medal” advantage. For example,

genetic science can now explain why some people, like champion Canadian cyclist Ryder Hesjedal, are “built” for endurance and maximum energy output. The average

lung capacity of a healthy male is about 6 litres, Ryder Hesjedal's capacity is 8.3 litres. That amount of extra air translates into more oxygen in the blood, which leads to enhanced performance.

Bob and Carol look at each other and confer. Bob wants to do it. Carol does not. They



decide to postpone the decision for 24 hours and have made an urgent call to you. Bob's argument is simple. The kinds of traits he wants to modify are already found in nature. Some people have some of them. Some people have others. Some people seem to have more of the right alleles for athletics than others. Bob feels that, since they have a choice, they should give Sarah every advantage that they can afford.

Should winning athletes give back gold medals because nature gave them certain genetic traits? They still have to work hard. So would Sarah. If Bob and Carol can afford to give her the "Gold Medal" advantage, why shouldn't they? Carol says she is uncomfortable with "genetic fiddling," as she calls it. She was

already uncomfortable with the screenings and choices they had to make that day about which embryo would survive and which would not. While she hopes her daughter will be interested in sports and will do well, Carol just does not think they should try to engineer all that. She just wants a child to love and care for, whatever her problems and her athletic abilities might be. It just feels "creepy" to her to do all this foisting of their desires on this child, even before it is implanted in her womb. Bob responds with, "being a good parent means giving your child every advantage and opportunity you are in a position to give." They stop talking, and wait for you to speak.

Discussion Questions

- 1) Bob and Carol are decent people trying to do the right thing. They each have a reasonable principle underlying their opposing points of view as they try to agree on what they should do. What do you think the principle is in their positions? What do you think of their arguments?
- 2) Bob makes the point that the genetic changes they will make already occur through natural methods of reproduction. What do you think of this argument? If something is found in nature are we morally justified in reproducing it scientifically? What principle is Bob using? Do you agree with it? Would it make a difference to you if one or more of the enhancements suggested involved a novel genetic innovation, say a method for rapidly removing waste products in the blood not found in nature?
- 3) The collection of genetic traits offered by the "Gold Medal" program has nothing to do with potential disorders or diseases. Does this make a difference to you? If "health" means psychological and social health as well as physical health, do you think that genetic engineering should take these factors into account and not just focus on physical diseases?
- 4) Some scientists believe that we can insert genes that do not "turn on" unless they are in the presence of a certain hormone. If this technology were used to delay the development of the desired traits in Sarah, delaying the decision until later, perhaps even involving Sarah's wishes as well, would this make a difference to you? Why or why not?
- 5) When the clinic representative handed the brochure to Bob and Carol, there were certainly commercial motivations. Should we always be presented with every possible option in the case of genetic modification? Should there be regulations guiding what can or cannot be offered by IVF clinics to the consumer?
- 6) What are the deeper implications of this type of genetic engineering for society? What are the implications for what we think it means to be a good parent?
- 7) Finally, what does this case imply about human nature, about what it means to be a human being? What do we, as people of faith, have to say to Bob and Carol about the goal and purpose of life?

Scenario 3

Question to Think About

If cloning were both possible and legal, do you see any ethical problem in using a dead child's DNA to clone another child, who would be the dead child's genetic "twin?"

Cloning is proving to be more difficult than at first anticipated, but, assuming that the technique could be perfected, we would then have to consider the outcome of using other people's DNA for cloning. Embryos and children developing from them would be genetic replicas. In cases such as in this scenario, couples might feel they owe it to the child who died to somehow use his or her DNA to reproduce the original child. What would happen to our experience of being unique, or of being wanted for ourselves, as opposed to being the product of someone else's DNA?

Narrative: Reproductive Cloning

You are the pastor of a large urban church in the near future. One of your parishioners, Alice, has come to your office for counseling on a specific issue that has come up with her business. Alice is an embryologist and the owner of an up-and-coming embryo research lab. They have successfully cloned non-human primates. The lab has a partner in Asia where laws regulating research are not as strict. The company is struggling financially, but Alice feels confident that they are working on important research that will ease human suffering. Her work on cloning human embryos for therapeutic purposes has produced very good results. Alice believes that she now has reliable techniques for performing nuclear transfer cloning. She tells you the following story.

Larry and Linda came to the lab a few weeks ago. Last year their 11-month-old son, Ted, died in the hospital. Because of an accident Larry is no longer able to produce sperm so they will not have another chance for biological offspring. The hospital was determined to be largely at fault. Larry and Linda were already very well off and the suit they filed produced an award of more than 30 million dollars. They had preserved tissue from Ted's body and presented it to Alice at the interview. They want Alice to attempt to use the tissue to produce a genetic clone of Ted. They are willing to put up 50 million dollars to carry out this genetic experiment. Alice's company can't do this work, but cloning for reproductive purposes can be done by her Asian partner. Larry and Linda seem to understand that this clone would not be "Ted" but his genetically identical twin.

Alice told Larry and Linda she would consider their offer and call them. At first Alice was inclined not to accept, but as she began to examine the idea she found herself having

less and less resistance to it. They would simply insert Ted's DNA into a donor egg, which would then be implanted in Linda's uterus. For all practical purposes the child would be their own son, raised with all the love and care that their child deserves.

They certainly have the means for raising a child and the means for taking advantage of cloning technologies. As far as safety goes Alice is confident that the risks are not greater than other legal reproductive technologies She has come to you because she remains unsure of the ethics of reproductive cloning. She wants your counsel as she approaches this important decision.

Discussion Questions

- 1) This case is not as far-fetched as it may sound at first. The desire to reproduce can be a very strong human drive. For people with money, for whom other techniques either do not work or do not provide enough genetic continuity, somatic cell transfer will be a considered option. What is your initial reaction to this? What are the reasons for your reaction?
- 2) Larry and Linda are wealthy. Is this important?
- 3) Assume that somatic cell transfer could be shown to be no more risky than other IVF techniques. Is this morally relevant?
- 4) Are there theological concerns that bear on this case? What does your faith tradition offer that might address the question of reproductive cloning? Is the method itself the problem? Safety concerns? What it implies about our self-understanding as human beings?
- 5) This scenario implies that privately funded research on reproductive cloning is not regulated. Do your concerns about cloning as part of IVF treatment lead you to believe it should be regulated? Banned?
- 6) Alter the scenario. Imagine that Larry wants to clone himself, instead of his dead son. The baby would be Larry's twin brother and son. How would this change your thinking? Why do "brother" and "son" produce a kind of uneasiness in many? Is this uneasiness connected to a moral concern or is it more a kind of "man, that's just creepy" reaction?