



CASE TEACHING NOTES

for

“Selecting the Perfect Baby: The Ethics of ‘Embryo Design’ ”

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INTRODUCTION

This dilemma/discussion case was designed for an introductory course in developmental psychology. Although the debate and doctors described are fictional, the case is based on actual events from the late 1990s that were extensively reported in the public press and in a documentary film.

In 1994, Jack and Lisa Nash had a daughter, Molly, who inherited a rare genetic disorder called Fanconi anemia. By having another child with specific genetic markers, the Nashes could utilize stem cells from the new baby's umbilical cord blood to effectively cure Molly. Their search for doctors to provide this type of pre-implantation genetic diagnosis and treatment was controversial. Screening their embryos to eliminate the genetic disorder in a second child was not the problem. The controversial step was to eliminate some healthy embryos and implant only those that matched Molly's needs. Eventually they were successful in obtaining the treatment. Molly now has a little brother whose umbilical cord blood was used to treat her. Currently, she appears to be doing fine. The [references](#) at the end of these notes include news accounts of the Nash case.

Prior to my use of cases in the classroom, I used the story of Jack and Lisa Nash to initiate student discussion. Students were eager to debate the ethical issues of genetic manipulation and fertility treatment. I observed that in previous semesters students easily identified with the parents in the story and with the suffering child. I wanted them to approach the issue from the scientist's point of view, so I wrote the fictional research team debate to frame the story.

My students generally have very little science background when presented with this case. Most only have a layperson's knowledge about genetics. They read basic information about the genetics of conception, prenatal tests, and developmental disorders in their developmental psychology text to supplement the case material.

The blocks of analysis and discussion involving some of these issues could be altered or eliminated if the case is used in other fields. Additionally, some objectives, such as those regarding the actual procedures, could be much more advanced than I have described here, when appropriate. Although the case was written for beginning developmental psychology students, I believe the issues raised involving genetic manipulation, advances in medical technology, and scientific ethics could be relevant in many other courses.

Objectives

- To demonstrate a basic understanding of how developmental disorders can be transmitted genetically, including the differences between disorders triggered by recessive genes, x-linked genes, and genetic mutation.
- To explain in-vitro fertilization and pre-implantation genetic diagnosis, including basic risks involved with the procedures.
- To consider and discuss ethical issues involved in these procedures.

MAJOR ISSUES

Developmental Disorders

Although the most interesting aspects of this case involve the ethical issues of genetic advances, students require a basic understanding of how disorders can be transmitted genetically in order to discuss this case. Fanconi anemia, named for Swiss pediatrician Guido Fanconi, is caused by a recessive gene. Larry and June, the parents, could both carry one recessive gene for Fanconi anemia without suffering from the disease themselves; they are still carriers. Sally received a recessive Fanconi gene from each parent. She carries the disease and suffers from it as well. Some other disorders linked to recessive genes include phenylketonuria (PKU), cystic fibrosis, and sickle cell anemia. It is important for students to understand recessive-linked disorders in order to discuss why the procedures proposed in the case will work and what the parents' other options might be. Students calculate the odds of inheriting a recessive-linked disorder if both parents are carriers. If the Shannons were to have another child, there would be a 25% chance the child would suffer from Fanconi anemia, a 50% chance the child would be a carrier with one dominant gene protecting him or her from the illness, and a 25% chance the child would be completely free of the faulty gene.

Fertility Procedures

Once these basics are established, the most interesting part of the case can be discussed. With students' help, review the steps in the process of in-vitro fertilization. Then add the steps necessary to pre-implantation genetic diagnosis. Discuss the ethical issues related to each procedure as you outline them. This helps students see how the procedures have become ethically more complicated as they become more advanced.

To perform in-vitro fertilization, the mother takes hormonal drugs to stimulate ripening of ova. Controversy continues over the long-term effect of these treatments. Several different drugs are used, with relatively common side effects ranging from mood swings to hot flashes, nausea, and headaches. Some studies associate the use of ovulation drugs with increased risk of ovarian cancer, but more recent research seems to indicate that the cancer risk is linked to infertility itself and not the drugs.

Ova are then harvested, fertilized with the father's sperm, and injected back into the mother's uterus. The harvesting of the ova is a minor surgical procedure, but sometimes requires anesthesia. The surgery carries the risks of complications present in any medical procedure, including minor risk of injury to internal structures or infection. Embryo implantation is usually a less complicated process, requiring no anesthesia. The hormone treatments and surgical procedures do require substantial investments of time and discomfort on the part of prospective mothers. The success rate of in-vitro fertilization is about 20%. It is an expensive and time-consuming procedure that couples often need to undergo several times before it is successful.

Pre-implantation genetic diagnosis involves testing fertilized ova before implanting them back in the mother's uterus. After ova are harvested and fertilized, doctors wait to see which survive and begin cell division. Once an embryo of several cells exists, a single cell is removed and tested for genetic defects. Embryos that are free of defects are implanted. Those that have genetic faults are discarded. At each step along the way, there is a chance that more embryos will die, so the number successfully fertilized will usually be smaller than the number that survive to be tested. The number that survive testing and are proven healthy will be even smaller. This reduces the chances of a successful implantation even further.

In the Shannons' case, this pre-implantation diagnosis goes one step further. After testing for genetic fault, another test will be done (on the same cell) for a genetic match to Sally. Again, this will effectively reduce the number of embryos found fit to implant, reducing the chances for a successful pregnancy. In the actual case, the couple had to go through the procedures at least twice before the resulting pregnancy was successful.

Along with the risks to the couple, I also have students discuss risks the research team run by becoming involved. These risks could include different types of liability, damage to reputations or careers (should the procedures at some later time be determined unethical), problems with peers who disagree with their decision, dissension within the team, or research funding problems.

Ethics

Ethical decision-making is the center of the lesson and should involve several general topics of discussion. The most obvious dilemma is about the ethics of the embryo selection procedure. Other problems include the effect on the sibling thus "created," the cost and access to such procedures, and the overall effects on society.

Questions you might pose for the class include:

- What is the difference between selection for healthy embryos and the selection that the Shannons propose? [The difference is that the proposed procedure selects for traits that are not of inherent benefit to the unborn child but will benefit another individual. Not only are embryos discarded when they carry an illness, but otherwise healthy embryos are discarded because they do not constitute a perfect genetic match for the existing child.]
- Is it ethical to select for traits that are non-health related?
- If you could select traits for your children, what would you want? What would you eliminate?
- Who should have access to this type of procedure? Only the wealthy? What effect would that have on society? If not by wealth, how do we decide?
- If we were to map everyone's genetic structure, what effect would that have on society? Would there be discrimination against those with less appealing genetic traits or with hidden genetic problems?
- What would be the psychological effects on people who discover they carry a hidden risk in their genes? [Point out that this is already a concern, now that many people can be tested for familial cancer genes.]

Some other possible issues include: Hormonal treatments' effects on women; how artificial methods of reproduction bypass nature; fertility treatments increasing chances of multiple pregnancies; implanting ova in surrogate mothers; and selecting genetically matched embryos to provide organs for transplants.

CLASSROOM MANAGEMENT

In my course students read the case and study questions individually; we then discuss the material as a class during the next meeting. Students later complete individual follow-up papers. This case could also be assigned for small group discussion. I have avoided this option because I find that students often have very strong opinions on reproductive issues. Conflicts between students are not uncommon and I prefer to have them take place when I am mediating the discussion.

Students complete the case as homework and use their text and other sources to help them with any background information on genetics that they might need. We spend the next hour (at least) of class time discussing the case. I usually begin the discussion by asking students what the Shannons want and what their possible options are. This can lead to a discussion of recessive-linked disorders and a calculation of the risk of having another child with Fanconi's anemia. Students can generate a list of options available to the couple, including the procedures outlined in the case. Center on these procedures and discuss the ethical problems related to each. I round out the discussion by turning to the research team in the case. Students present their views on what the research team's dilemma is and the risks they run. We list their options and conclude by taking a vote on what the research team should do.

Various other assignments can be completed for this case. I have had students choose a genetic marker in their own family and draw a family tree tracing it through as many generations as they can. (I do not share this work with the class.) My students also complete an "Informed Opinion Paper" after the discussion in which they address any or all of the following questions: If a problem were suspected during a pregnancy, would you want to know? Would you consider using IVF or PGD yourself? Why or why not? What do you think is the most important ethical issue associated with PGD? Describe both sides of the issue.

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