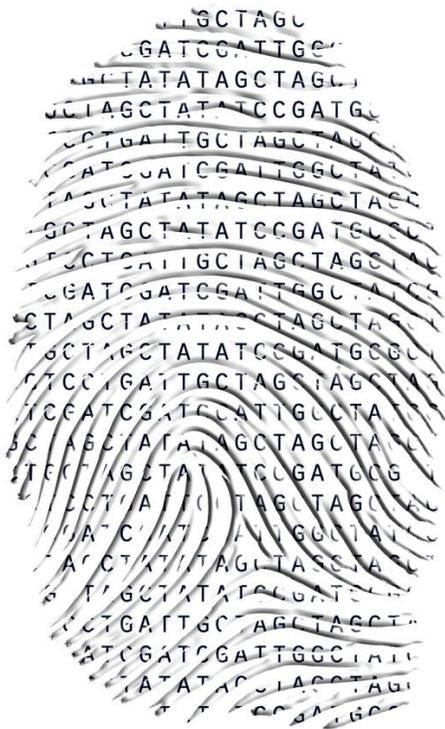


Introduction

The film "Gattaca" follows a familiar storyline. Boy meets girl. Girl likes boy. Boy and girl perform the dating ritual. They disclose information about each other. They talk about their dreams.

The story takes an unexpected turn when girl tells boy she's had boy genetically sequenced and profiled. Girl apologizes. Girl then confesses to boy that she has a heart problem. Boy seems unmoved by girl's confession. Girl pulls a hair from her head and

gives to boy and says, "If you don't believe me, take this. If you're still interested, let me know." Boy holds the hair, looks at it for a moment, looks at girl, lets the hair go and says, "Sorry, the wind caught it."



We are now able to test for well over a thousand genetic diseases, disorders, and traits. New tests are developed almost every day. Techniques for doing many tests at once and doing them cheaply are in the works. In this session, we will discuss a few of the many puzzles that arise because of our rapidly expanding ability to create comprehensive genetic profiles of individuals. The infamous O. J. Simpson case catapulted the concept of DNA evidence into the public eye. It is now a routine part of forensic science. But this is just the tip of the proverbial iceberg.

According to technology critic Neil Postman, every technology has within it at least one big idea. What is the big idea embedded in genetic technology? Is it that everything of value to us can be discovered in the structure and function of our genes? We might not like our genetic profile, but according to that big idea it is immutable. How is our capacity to sequence and analyze our DNA likely to affect our self-understanding and the way we interact with each other? Will it change our social institutions, our way of judging the suitability of people to be husbands, wives, fathers, mothers, sons, daughters, employees?

Scenario 1

Question to Think About

How will increased knowledge of genes and their significance affect our social lives?

Although the first narrative focuses on dating, it is easy to extrapolate from this to other social rituals and institutions. How will daily life change as genetic profiling becomes increasingly possible?

Narrative: The New Dating Ritual

Ginny and Kevin have been dating for some time and now they are both ready to take their relationship to another level. Kevin proposes and Ginny accepts. They realize that they are now committed to a common destiny and will need to plan their future together. Before they announce their intentions to their families and friends, they agree that they need to undergo medical examinations to ensure their compatibility and expectations of a healthy life together. They agree that along with tests for HIV and other sexually transmitted diseases they should also find out everything they can about their genetic profiles. Kevin and Ginny consider this to be simply a matter of taking responsibility.

Review Genetics 101 to refresh your memory on the relationship between genes and genetic traits. The section on Genetic Testing will also be helpful to understand the basics of testing for various genes associated with certain traits.

Discussion Questions

- 1) One purpose of dating is for couples to get to know each other to see if they are compatible. Couples learn about each other's history and each other's families. Is learning about each other's genetic traits simply another part of that?
- 2) Embedded in every technology is an idea – usually a very powerful idea – that has the capacity for changing the way we think about life. What is the idea embedded in our ability to learn about someone's genetic profile?
- 3) As genetic testing becomes routine and affordable this scenario will become increasingly plausible. Should there be regulations about such testing? What kind, and how would they be enforced?

Scenario 2

Question to Think About

Is genetic testing for those planning to have children a responsible thing to do?

You may want to review Genetics 101 and review terms in the glossary such as *allele*, *phenotype*, *genotype*, and other terms mentioned in Genetics 101.

Scenario Two looks at pre-conception genetic decision-making. When a couple thinks about having children and the future of their children, the issues become complex. There are some instances where both potential parents may be carriers of a specific disease, for example, and their offspring may well develop it. With diseases such as Tay-Sachs, a couple may decide to

remain childless or even not marry.

Parents want to provide the best possible future for their children. This scenario asks how far that hope should be carried.

Narrative: Pre-conception Screening

You are a pastor in a clinic. Julie and Frank have made an appointment with you to talk about their plans to have a child. They are not yet pregnant. Julie is a university student and is taking a course on genetics. She has learned a great deal about genetic science and understands that their children will inherit alleles from both parents, and that these combinations could be detrimental to their offspring. Julie wants them both to undergo an extensive battery of genetic screenings before conceiving, so they can assess the genetic risks associated with conceiving a child together. Neither Frank nor Julie wants to have an abortion, so they hope that by screening themselves they can decide whether to conceive or adopt.

Julie says that a couple they know have three children and each child has the same genetic disorder, which has led to stunted growth and developmental problems. One of the children developed an autism-related disorder and is institutionalized. Neither parent had any family history to suggest that one or both of them were carriers for this disorder. Julie hands you a brochure from a genetic testing advocacy group that makes the argument that, given the state of genetic testing technologies, it is irresponsible for any prospective parent not to take these tests in order to avoid genetic tragedies like that which befell Julie's friends.

Frank is not in favour of the genetic screenings but admits that he does not know much about genetics and is willing to do what Julie wants provided you, their pastor, support this important decision.

Discussion Questions

- 1) How should you respond to the genetic information that Julie brings to the conversation? To what extent is this science relevant for your thinking? Is it necessary for Frank to get up to speed with the science? Can you effectively proceed with your counseling role in this case without having some understanding of genetics?
- 2) What might be the psychological and social consequences if Julie and Frank decide to proceed or not to proceed with these tests?
- 3) What counsel would you give Julie and Frank?
- 4) If Julie and Frank were to instead come to you for pre-marital counseling, would your mind change on any of these issues?



Scenario 3

Question to Think About

Will genetic knowledge change the way we think about reproduction?

This question explores the larger issue of reproduction itself. In this scenario, a couple has reproductive choices put before them by their insurance company, the imaginary GenLife Insurance Inc. The ideas found in this scenario are implied in the logic of the insurance company and the natural desire on the part of potential parents to do what they can to bring a healthy child into the world.

Narrative: Pre-implantation Screening

Before you consider this story you may wish to review Embryo Development and Genetic Engineering. In addition, you may wish to review in the glossary some of the terms used in this scenario, for example, *in vitro* fertilization, pre-implantation genetic screening.

George and Melinda live in Ontario ten years in the future. They have decided they want to have a child. Melinda has health benefits through her employer, a major university. When they examine her policy this is what they find.

GenLife is committed to quality health care at an affordable price. You want a healthy child and we will help you achieve this goal. We will cover 100% of your prenatal and birthing costs provided you meet the following conditions:

- *You must agree to have your embryo or fetus screened for all known genetic disorders, defects, and disabilities. We will do this either in utero or through in vitro fertilization (our much preferred method). All costs associated with this screening will be assumed by GenLife.*
- *If the screening reveals genetic markers raising the probability that your child (if you bring the embryo to term) would develop a genetic disorder or disability you will have two options:*
 - 1) *Discard the embryo/fetus and repeat the process. GenLife will cover the cost of discarding the embryo/fetus and work with you as many times as necessary to produce an embryo free of potentially costly genetic anomalies that could pose a threat to your future child 's health and greatly increase health care costs.*
 - 2) *Keep the embryo and assume full financial responsibility for the treatment of the discovered condition(s) should it (they) develop.*

- *GenLife WILL NOT cover prenatal or birthing costs should you elect to carry an unscreened embryo to term.*
- *GenLife WILL offer health insurance to your unscreened child but at a cost commensurate with increased risks associated with unscreened embryos.*

Be aware that your unscreened child will always be a member of a high-risk pool and will be required to pay higher premiums. Also be aware that if you choose to carry an embryo to term with a known risk for a disorder or disability they will never be covered for that disorder or disability by GenLife.

THIS PROCEDURE IS NOT MANDATORY. If you elect not to have your embryo or fetus tested we WILL cover your child once born, but premiums will be commensurate with his or her unscreened risk pool, which is significantly higher than for screened pools. We also offer two enhanced prenatal programs described below.

GenLife Fetal Selection Program (GFSP)

Under the GFSP program we will help you produce 20 embryos through IVF. As with the standard screening program these embryos will be carefully screened for genetic disorders and disabilities. In addition we will test for all known genetically influenced traits, such as sex, height, skin, hair and eye colour, etc. We will then assist you in selecting not only the healthiest but also the most desirable based on your own needs. We understand that you want to give your child every possible advantage. We're here to help. COST: \$45,000

GenLife Fetal Enhancement Program (GFEP)

Under the GFEP program you not only receive the benefits of the standard screening and Fetal Selection programs, you are also able to take advantage of the latest developments in germline intervention technology. This technology uses artificial chromosome technology to actually tailor the genetic profile of your child. There are currently 6 alterations known to be safe and effective. Many others are being developed. With current technology you have the ability to virtually guarantee a healthy baby with traits known to be advantageous in today's competitive world. Our extensive research shows that your child's genetic profile is the single most important factor for health, longevity and quality of life. We are so confident that you will be pleased with the results that we will reduce the standard screened embryo premium by half and guarantee these rates for the life of your child. Expensive? Yes. But how much is your child's health worth? COST: \$180,000.

Discussion Questions

- 1) What do you think about an insurance company that tells you that if you use in vitro fertilization you must agree to have your fetus or embryo screened for genetic defects?
- 2) Are the options GenLife offers morally acceptable to you? Why? Why not?
- 3) Assuming such programs would be legal, what do you think about GenLife's Fetal Selection and Fetal Enhancement Programs?