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SNAPSHOT
Mini-Lesson

Educational Resource for
Students & General Audiences

Who Are Genetic Counselors?

PERSONAL
GENETICS
EDUCATION
PROJECT

ETHICAL, LEGAL, & SOCIAL ISSUES IN PERSONAL GENETICS

Guiding Questions:

- Who are genetic counselors?
- What role do genetic counselors serve as healthcare providers?
- How do genetic counselors help people understand their genetic health information?

Genetic counselors (GCs) are trained healthcare specialists with expertise in medical genetics and counseling. Think of GCs as helpful guides and advocates for patients as they navigate their journeys in genetics.

What can people learn from genetic testing?

Genetic tests can provide useful information for making healthcare decisions. However, patients often find it difficult to understand what the tests are looking for and what the results mean. Currently, there are more than 77,000 genetic tests on the market, with about 10 new tests being added daily. These genetic tests differ from each other in what they look for in a person's DNA. Some of these tests look at chromosomes. If you think of a person's DNA as a city, chromosomes are like the neighborhoods in that city, with each neighborhood carrying a part of the total DNA. Genetic tests that look at entire chromosomes may look for duplicated or missing sections of a chromosome or count the total number of chromosomes in a cell. Other tests look at the DNA at a much smaller scale, such as genes. In our city analogy, a gene is like a house in one of the neighborhoods. Some genetic tests just look at a single gene that is known to be related to a specific health condition.

In addition to differences in what genetic tests look for in a person's DNA, there are also differences in what types of results they give. Sometimes the results can predict someone's risk of developing a condition in the future, even though they do not have any symptoms. In other instances, a single gene might be analyzed to diagnose a genetic condition in a person with active symptoms.

How does someone decide which genetic test is appropriate for them? And how do they manage expectations and correctly interpret the results? Fortunately, there are healthcare professionals called **Genetic counselors** who can help with this overwhelming process. Genetic counselors interpret and communicate complex genetic information to patients in clinical settings. GCs empower patients and their families with information, guidance, and emotional support. They help patients understand their genetic risks based on family history, evaluate genetic testing options, and make informed decisions based on their results.

GCs often work in medical specialties such as cancer, prenatal, pediatrics, neurology, and cardiology. They are important members of the healthcare team and often collaborate with other providers such as doctors, nurses, and specialists, to deliver patient care. Today, over 5,600 board-certified genetic counselors are working in the United States.

When might a person meet with a GC?

There are many scenarios in which an individual or family may want to speak with a genetic counselor. Many people seek genetic counseling if they have a pattern of a genetic condition in their family (family history). For example, if someone has several family members with breast or ovarian cancer, genetic counseling might be helpful to understand whether they are at risk of the same health condition. Other examples of when patients seek help from a GC include the following:

- A patient is pregnant, or considering pregnancy, and has questions about potential genetic risks to the baby.
- A patient, or their family members, have an unexplained medical concern that could be due to genetic causes.
- A patient has limited information about their biological family (e.g. due to being adopted) and is curious if they are at risk for any inherited conditions.

Whichever the case may be, GCs can provide patients with information about genetics, inheritance, specific genetic conditions, and so on - and can help develop a personalized health plan for patients and their families.

How can a GC help people understand the risks and benefits of genetic testing?

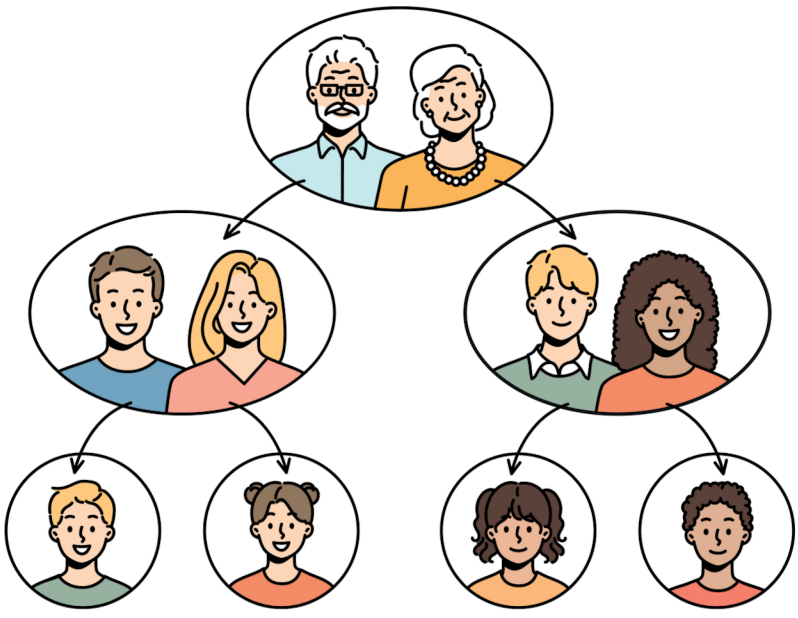
Patients are increasingly including genetic testing in their medical care. But with tens of thousands of tests available, navigating this process is complicated. GCs help patients understand what tests, if any, may be right for their given scenario - and discuss the benefits, risks, and limitations of genetic testing. GCs ensure that the right genetic test is ordered to avoid unnecessary costs and they prepare patients mentally and emotionally to receive results that may be surprising or alarming.

Not everyone who sees a GC will undergo genetic testing. Sometimes, there is no test available. Other times, patients choose not to undergo testing due to personal values, goals, beliefs, or culture. GCs can help patients think of scenarios that they have not considered, and provide guidance and psychological support throughout an individual's or family's decision-making process.

How can a GC help a person process the emotional implications of genetic testing?

The interpretation of genetic testing results is complex and requires independent investigation. Therefore, GCs prepare for each case by digging into scientific literature, synthesizing the information, and translating the patient's results into non-technical language. Depending on the situation, receiving a genetic diagnosis can be confusing, create anxiety, or feel like a breakthrough. In addition to providing emotional support, genetic counselors can equip patients with appropriate resources and connect them to patient organizations or community support services as they adapt to new knowledge about their health.

Often GCs serve as advocates to not only the patient sitting in front of them but also for other family members who want to learn about their disease risk. The results of genetic testing for an individual can often identify other family members at risk for developing the same condition. However, not all people want to know about their genetic information due to factors like timing, stress, privacy, and discrimination concerns. When GCs discover information about disease risk for family members, they can write letters for patients to send to their relatives. These letters inform the family members that they may be at risk, what that means, and offer concrete steps they can take if they wish to learn more. This approach strikes a balance between alerting family members of potential disease risks while offering them the opportunity to choose how much information they wish to know.



Genetic counselors are important members of the healthcare team who help patients and families navigate their journeys in genetics. GCs can help patients understand their disease risk, and how their condition may be passed on, manage expectations around genetic testing, and clarify the results so that patients can feel empowered to make informed decisions regarding their health care.

Student Worksheet

Name: _____ Date: _____

Directions: Answer the following reflection questions to showcase your understanding of the genetic counseling process.

1) When might you seek the help of a genetic counselor? Write down two possible scenarios.

2) One reason why an individual might not decide to undergo genetic testing is they feel that, given current stressors in their lives, it is not the right time to find out potentially upsetting information about disease risk. Can you think of two other reasons why some people might not choose to undergo genetic testing?

3) Would you want to take a genetic test to know if you are at risk for developing a health condition if there was no cure or treatment available? Why or why not?