Common Genetics and Genetic Counseling Myths: Debunked

By Chani Wiesman Berliant

Genetics is one of those fields that may be shrouded in mystery and perhaps even fright. This is because serious genetic problems are very rare, and therefore most people have never needed to delve into the field or meet with a genetics professional. However, as the use of genetic testing is becoming more widespread and genetic technologies and the scientific understanding of genetics advance, so should the community’s understanding of genetics.

Here are four common myths about genetics and genetic counseling that I hear from patients, colleagues, and friends. These misconceptions need to be debunked!

1. If my partner and I are tested and we are not a genetic “match,” then we can’t have healthy children and we shouldn’t get married.

What you decide to do with the results of your genetic testing is your own choice, but there may be more reproductive options than you think. If both members of a couple are carriers of the same genetic disease, there are still ways for them to have unaffected children. First, with autosomal recessive diseases, such as Tay-Sachs disease or cystic fibrosis, there is only a 1 in 4 chance in each pregnancy for a ‘carrier couple’ to have a child with the disease. Therefore, there is a 3 in 4 chance for them to have an unaffected child in each pregnancy. So to begin with, the chances are higher that they would have healthy children. That being said, an unlucky couple could potentially have 5 affected children in a row. This is unlikely, but definitely possible. Genetic testing of a fetus could pursue in vitro fertilization (IVF), then test the embryos prior to implantation, and only implant unaffected embryos.

2. If I meet with a genetic counselor, I am going to end up needing to terminate the pregnancy or to consider pregnancy termination.

I hear this “worst case scenario” anxiety relating to many areas of genetics and genetic counseling. “If I have BRCA testing, I’m going to end up having a mastectomy and also removing my ovaries”; “If I have prenatal genetic counseling or testing like an amniocentesis, I am going to be forced to terminate the pregnancy.” The truth is that genetic testing and subsequent measures are always the choice of the patient. This is ensured by the process of genetic counseling which is non-directive in nature. Even if you meet with a genetic counselor, you will only have genetic testing if that’s what you decide to do. (I have patients who decline genetic testing all the time!) Genetic coun-

3. Genetic testing will tell me everything I’ve ever wanted to know about myself and my future medical problems.

Genetic technologies have advanced exponentially over the last 30 years. At this point, we could take a look at all of your 30,000 genes for around $5000. (We’re not at the “thousand dollar-genome” quite yet!) While this technology is exciting, the very important piece which has been lagging behind is our ability to interpret all of the results. We don’t yet understand the consequences of all variations in the genome. Many studies have reported certain “genetic links” to various medical issues, but the medical community is not sure if this is the full picture. We also don’t yet understand the full interplay between our genes or the effect of the environment on our genes. The future is promising, but at this point, the single best predictor of future medical problems remains the family medical history.

4. My family seems to be the only one who has a “genetic issue.”

Rare problems, whether spontaneous or inherited, can happen in any community or family. Sometimes, medical issues such as diabetes, mental illness, deafness, and cancer may run in families. However, there are a variety of reasons why you may have never heard about them. In the generations following the Holocaust, many people did not have access to their family’s medical history. Additionally, many individuals do not discuss their personal or family’s medical history, possibly out of privacy considerations or for fear of stigmatization. You might not know about a medical issue, not because it isn’t there, but because people don’t talk about it. Often, all it takes is having someone begin talking about the genetic issues in their family, for others to open up, share their family stories, and offer support and resources.

In upcoming years, the scientific community’s understanding of genetics will continue to increase and genetics will become more and more integrated into routine medical care. This is one reason that our community needs to start addressing some of the widespread misconceptions about genetics and genetic testing. We need to take the initiative to educate ourselves about the possible implications of genetics on our health and the health of our future generations.

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Genetic counseling is non-directive in nature, and counselors are there to make sure that you understand the variables and that the decisions you make are in line with your beliefs, concerns, and values.

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