BIOETHICS

E GENOME GENERATION

Ethics of Genetic Testing in Cancer





BIOETHICS

Ethics of Genetic Testing in Cancer, Part 1

Are genetics everything?

a.	Monica is only 25 years old and was diagnosed with a disease that is more common
	to older adults. Monica may think back to all the times she forgot to wear sunscreen
	and feel like this was her fault. What could Dr. Ortiz tell Monica to help her cope
	with her diagnosis?

b. Imagine a person has a family history of skin cancer. Should this person get screened for germline/inherited gene variants associated with increased risk for skin cancer? Why or why not? What factors would contribute to their decision?

c. Simply having one gene variant associated with risk does not guarantee a cancer diagnosis. If a person found out they had a gene variant that confers risk for skin cancer, should they change their behavior to lower the risk? If yes, how?

BIOETHICS

Ethics of Genetic Testing in Cancer, Part 2

Medical consent and respecting other's medical decisions

There are times when a family member does not agree with medical decisions another family member has made. If one family member uncovers genetic information about themselves, it could have significant implications for other members of the family. Not everyone will actively consent to being informed of genetic data that is shared within a family. Additionally, babies receiving newborn sequencing cannot consent to this.

1. Imagine a young adult in her early 20s decides to get genetic testing because her maternal grandmother and maternal uncle both had breast cancer. She finds out that she carries a gene variant putting her at high risk for breast and ovarian cancer. She is now able to get a higher level of preventative care so that doctors could identify cancer at an earlier stage. Her mother, who is in her 40s, does not want to know if she carries a high-risk gene variant. Because it is highly likely the young adult inherited the gene variant from her mother, should she tell her mother about the gene variant even if she doesn't want to know? What factors play into her decision?

2. Parents are given power to make medical decisions for their minor children. Parents face such decisions on a regular basis, from selecting medications, signing off on surgery, or deciding whether to vaccinate their children. Is it ethical that parents make the decision to get their baby sequenced when the baby cannot consent to this and yet it has implications affecting their entire life?

Resource

Personal Genetics Education Project – Introduction to Personal Genetics