Interpreting Risk — The Impact Of Life Experiences

Background:

Approximately 5-10% of women with breast cancer have an inherited form of the disease. Scientists discovered several genes involved in breast cancer in the mid to late 1990's. Two such genes are BRCA1 and BRCA2. While every woman has a 12% lifetime risk of developing breast cancer, women with a mutation in one of those genes has significantly higher risk.

At this time there is no cure for breast cancer. While some studies have suggested that there are medications and surgeries that may reduce a woman's risk of getting breast cancer, the results are indecisive. It is clear, however, that early diagnosis and treatment greatly improves a woman's chance for survival. Women who have close family members with breast or ovarian cancer (especially early-onset) or who are known to have genetic changes in one of the breast cancer genes are encouraged to have earlier and more frequent screening mammograms and clinical breast exams, in addition to performing breast self-exams. In this way, it is hoped that any evidence of breast cancer will be found early and result in early treatment and long-term survival.

Vignette:

Lisa and Tonya are college roommates. They agree on almost everything but reacted very differently to an advertisement they saw in the local newspaper: A company was offering a simple blood test to screen for mutations in the BRCA1 and BRCA2 genes.

Tonya's 44-year-old mom was just recently diagnosed with breast cancer. Fortunately, the disease was diagnosed early and successfully treated by removing the small lump from her breast. Tonya's mom is now feeling great and has fully recovered from the surgery. Lisa, on the other hand, has had a very different experience with the disease. When her mom was diagnosed with breast cancer at age 45, the cancer had already spread to other parts of her body. After two agonizing years of chemo- and radiation therapy, Lisa's mom died. It was a month before Lisa's high-school graduation.

Lisa desperately wants the genetic test. At this time, she feels convinced it will be just a matter of time before she will get breast cancer and die from it. She also says, that although she wants to have children some day, she won't if she is found to have one of the mutations in BRCA1 or BRCA2. She says she would rather adopt children than risk passing it on to her children.

Tonya thinks the test is unnecessary. She says it costs too much and has heard how hard it is to get health insurance if you don't 'pass' a genetic test. Tonya believes that having a genetic test is just not worth the risks involved. She decides she will do self breast-exams regularly, since that is how her mom initially found her lump. She will also start having regular mammograms sometime in her 20s. She feels that while she may one day get breast cancer, she will catch it early and do as well as her mother did.

Discussion points:

Why do you suppose Tonya and Lisa have had very different reactions to the availability of the genetic test for breast cancer?

How important do you think knowing this information is to Tonya? To Lisa?

What scientific, medical and societal information should each consider before deciding whether or not to take the gene test?

What are the potential benefits of the test?
For Tonya? For Lisa?

What risks are associated with genetic testing?
Do you think there are risks to family members of Tonya or Lisa?

Do you think the identification of a BRCA1 or BRCA2 mutations would have an impact on how people monitor themselves for breast cancer?

How would the identification of a genetic mutation change your surveillance?

If Tonya or Lisa decide to go ahead and have a genetic test, but no mutations is found, can they safely assume that there is NO chance that they will ever develop breast cancer?