

Testing for hereditary breast cancer? Toolkit helps families talk, cope, decide what to do

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Actress Angelina Jolie made headlines in May when she revealed she underwent a preventive double mastectomy to reduce her risk of cancer.

According to the New York Times, Jolie carried a genetic mutation in the BRCA1 gene, which elevated her chances of breast and ovarian cancer to 87 percent and 50 percent, respectively. She also has opted to have her ovaries removed.

Discussing the genetic mutation in the family can be very difficult. To that end, Maria Katapodi, associate professor at the University of Michigan School of Nursing, developed the Family Gene Toolkit to help families communicate about the mutation, elevated [cancer risk](#) and the importance of genetic testing.

By involving entire families, the kit aims to take the burden of disclosure and explaining complex genetic information away from the mutation carrier, Katapodi said. The hope is that these discussions occur soon after a mutation is detected in one family member and before other members develop cancer.

"Our goal is to help families have open communication, cope and make better decisions when someone learns they are a carrier of a cancer [gene mutation](#)," she said.

Jolie's story renewed the debate over genetic testing and pre-emptive surgery when a BRCA1 or BRCA2 mutation is present. Several of her

family members, including her mother and aunt, died of ovarian or [breast cancer](#). Jolie's aunt, who carried the mutation but didn't know it, died just weeks after Jolie's announcement.

"Cancers caused by these genes may be more aggressive and affect younger people, so they take away more years of life, Katapodi said. "If you know you have a high chance of getting cancer, you can consider issues like fertility and family planning, career and life goals before you make a decision on treatment."

"You can really look at the big picture. You're not just someone with a genetic mutation. You're a person with feelings, a woman, a mother, you have aspirations for a career."

Katapodi's toolkit includes two live Internet counseling sessions with a genetic counselor and an oncology nurse. The sessions cover basic information about genes and genetic testing, as well as coping mechanisms and communication among family members. The program also includes follow-up phone calls to answer any outstanding questions.

More information: Family Gene Toolkit:
sites.google.com/a/umich.edu/familygenetoolkit

Provided by University of Michigan

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