

## Too much and too little: Delicate balance of knowing risk and treating disease

Modern definitions of 'incidentals': The travel-sized odds and ends in the corner of the airport news shop; The bottle of water or candy bar you pick up during a conference and expense to your company; The devastating news you have an extremely high risk for developing stomach cancer reported from a breast cancer screening test.

Jennifer, 39, had a grandmother that died young from breast cancer. So, as reported in the New York Times, she decided to get tested. The genetic counselor offered her a panel of 20 other mutations linked to cancers that could be included, and Jennifer said yes. [In retrospect she questioned the decision:](#)

The results, she said, were "surreal." She did not have mutations in the breast cancer genes, but did have one linked to a high risk of stomach cancer. In people with a family history of the disease, that mutation is considered so risky that patients who are not even sick are often advised to have their stomachs removed.

But Jennifer's family had no history of stomach cancer, so it was impossible to know, even for her doctors, what to do with this information. Should she have a radical surgery based only on this genetic risk factor?

These are the questions that arise from 'incidental findings' in genetic screenings. These results weren't what a patient or physician was looking for, in Jennifer's case her breast cancer risk. But, they are significant, at least in the way we currently understand genetics. And as screening becomes cheaper and more common, [incidental findings are on the rise](#):

Mary-Claire King, a professor of medicine and genome sciences at the University of Washington who helped discover the BRCA1 gene, said that laboratories should not even report variants of unknown significance to doctors and patients. "We need to report back only what is devastating and clearly devastating," she said. "Patients and their physicians need to have information that they can act on and they can act on with clarity."

Now compare Jennifer's story to that of Ezekiel Emanuel, the director of clinical bioethics at the National Institutes of Health. It's unlikely Emanuel will ever be faced with an incidental finding because he's decided not to look for any risk factors. In fact, as [Emanuel controversy wrote in the Atlantic this month, he'd like to die quickly at age 75](#). To do so, he'll stop even preventative screening measures:

This means colonoscopies and other cancer-screening tests are out—and before 75. If I were diagnosed with cancer now, at 57, I would probably be treated, unless the prognosis was very poor. But 65 will be my last colonoscopy. No screening for prostate cancer at any age. (When a urologist gave me a PSA test even after I said I wasn't interested and called me with the results, I hung up before he could tell me. He ordered the test for himself, I told him, not for me.) After 75, if I develop cancer, I will refuse treatment. Similarly, no cardiac stress test.

These patients could not have a more different approach to their medical care. And that's probably reasonable. Nearing 40, Jennifer still has two young children to look after. Emanuel will be 60 soon. His children are grown. They are both valuing their quality of life, but through the prisms of different generations.

And both patients require a medical care system sophisticated enough to understand both risk profiles and patients' desires to limit their own self-knowledge in deference to peace of mind. That is a complicated balance for a physician who might treat both of these people. And likely one many doctors will have to account for in the coming years.

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#### **Additional Resources:**

- [What should be done with unsettling 'incidental findings' in gene screens?](#), Genetic Literacy Project
- [Personal genetics consumers risk uncovering uncertain paternity](#), Vox
- [New guidelines for patients who opt-out of DNA screens too limiting](#), Genetic Literacy Project