# Our obsession with hereditary cancers didn't start when we discovered the breast cancer gene

August 19 2015, by Devon Stillwell

Angelina Jolie received much public attention for her decisions to undergo first a prophylactic double mastectomy and, later, prophylactic surgery to remove her ovaries and fallopian tubes.

The procedures were Jolie's response to learning she had the BRCA 1 gene mutation, which predisposes women to a higher-than-average cancer risk.

She framed her choices within her family history (her mother died from cancer at 56), her own disease risk and her motivation to stay healthy for her children.

Featured on Time's May 27 2013 cover, titled "The Angelina Effect," the actress was celebrated for promoting awareness about the connection between genetics, risk and health to the extent that doctors anticipated being overwhelmed by a "stampede of women" requesting genetic testing for their BRCA status.

The discovery of the BRCA genes (and the resulting genetic tests) in the early 1990s is often touted as the watershed moment when genetics and heredity became important to cancer. This is not, however, the case.

We did not suddenly recognize that some cancers are hereditary once we could test for gene mutations.

Looking back at this history shows how scientists and the public tried to understand hereditary cancer risk well before we had the technology to discover mutations and test for genetic disorders. This history also demonstrates that the experience of hereditary disease and genetic testing is deeply gendered, affecting women and their reproductive choices.

## Understanding hereditary cancer – a brief history

BRCA mutations account for 5%-10% of all breast cancers – yet discussion about cancer and risk have been, and continue to be, profoundly shaped by genetics.

But researchers had identified that some cancers, like breast cancer, could be hereditary as far back as the early 20th century.

In the 1910s, the Eugenics Record Office, headed by Charles Benedict Davenport, conducted research on hereditary cancers, collecting information on "cancer families" through pedigree charts and detailed medical histories.

Back then, people wanted to know about hereditary cancers for the same reason people might want to be tested for the BRCA mutation today – to understand their own risk and to make decisions about when or if to have children.

We can see this reflected in letters doctors wrote to the Journal of the American Medical Association in the 1930s. One doctor asked how to counsel "a young married couple with regards to their bearing of children in view of [their] cancer history." Another, inquiring for his patients, wondered whether any tests or examinations existed that could predict cancer in a given family.

In 1958, Sheldon Reed, V Elving Anderson and Harold O Goodman, all researchers at the Dight Institute for Human Genetics at the University of Minnesota, published Variables Related to Human Breast Cancer. The book was a result of a 13-year inquiry into familial clustering of the disease. They concluded that:

*"mothers, sisters, and daughters of breast cancer patients have a risk of developing breast cancer which is about twice that of other women of the same age."*

Reed, Anderson and Goodman counseled "at risk" women to consult their physicians for frequent breast exams and for surveillance of "subclinical or pre-pathological signs" in order to catch cancer in its "pre-disease" state. This concept of "pre-cancer" struck a chord with many. Americans concerned about their health (and women in particular) contacted the institute for risk estimates and genetic counseling based on their family history. This may sound familiar to many women today.

By the 1960s, Henry T Lynch, the "father of cancer genetics," popularized the importance of heredity to cancer control and prevention efforts. He created a system of predisease detection for people at risk for hereditary cancers to help them make proactive health decisions. Lynch suggested that women should be taught to perform a breast self-exam and seek annual mammograms. Knowing's one's risk, he estimated, promoted vigilant surveillance and early diagnosis, maximizing women's sense of control over their health and management options.

In all these examples, you may notice a pattern: women (with the help of researchers) were seeking ways to understand and mitigate their cancer risk in order to control their personal and familial futures. We see the same pattern reflected with genetic testing today. Whether for cancer or for other health issues, it has become largely a women's issue.

# Genetic testing and women

For decades, scholars have analyzed how genetic tests like amniocentesis and chorionic villus sampling (CVS), as well as technologies like in vitro fertilization, have affected women's reproductive choices.

Genetic testing for BRCA prompts us to revisit some of the central questions these scholars raise. How are women's reproductive choices influenced by the prospect of a disease like breast cancer that appears in adulthood?

As genetics becomes *the* paradigm for understanding disease, how does it affect how women think of their reproductive options? How does thinking in terms of genetic risk affect women's psychological and emotional well-being, and how they conceptualize their family life?

BRCA testing also asks us to consider a larger problem in women's health history: the tendency to think of disease solely in terms of personal risk. Considering environmental health risks helps us to think more about collective impacts and responsibilities. But genomic medicine tends to emphasize uniquely personal risk factors.

This emphasis on personal risk may lead us to ignore the wider range of social and familial factors that affect how women interpret their health status and experience genetic disease.

We risk thinking about genetics as destiny, as though it is only hereditary risk factors that matter. Taken to the extreme, that might mean deemphasizing important nongenetic measures that have curbed cancer risks for decades.

Pap smears, mammograms, prophylactic medications and other public health initiatives have all helped increase early detection of cancers. The

predisease infrastructure erected with the help of post-WWII geneticists like Reed and Lynch is now being overshadowed by predictive technologies of the "new" genetics.

Women's experiences with health, illness and living "at risk" serve as grounds for debating social values around motherhood, reproductive rights, and concepts of disability and disease. BRCA is not the first platform for debating these issues, nor will it be the last.

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