

Familial Risk of Cancer and Knowledge and Use of Genetic Testing in the US

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Family History is the Key to Personalized Medicine

"Personalized medicine" targets healthcare based on genomic information ("genetically-enabled healthcare")

Background & Objective

- Identification of genetic markers for common diseases, including cancer, highlights the importance of familial risk assessment.
- Little is known about patterns of familial cancer risk in the general population, or whether this risk is associated with knowledge and use of genetic testing.
- Many barriers to collecting this information in practice.
- To examine the distribution of familial cancer risk and its associations with genetic testing in the United States.

Design

- Cross-sectional analysis of the 2005 National Health Interview Survey (NHIS).
- 31,428 adults.
- Familial cancer risk was categorized based on:
 - number of first-degree relatives with a breast and ovarian cancer syndrome (BRCA)- or a hereditary nonpolyposis colorectal cancer syndrome (HNPCC)-associated cancer (CRC and uterine)
 - age of onset (< 50 or ≥ 50 years)
 - personal history of any cancer
- Outcomes:
 - *heard* of genetic testing
 - *discussed* genetic testing with a physician
 - *advised* by a physician to have testing
 - *received* genetic testing

Key Results

- Family history of BRCA- or HNPCC-associated cancer:
 - 84.5% had none
 - 12.9% had a single first-degree relative (5.3% with early onset)
 - 2.7% had ≥2 first-degree relatives
- 40.2% of adults had *heard* of genetic testing for cancer risk
 - Only 5.6% of these individuals had *discussed* testing with a physician
 - Of these 36.9% were *advised* to be tested.
 - Overall only 1.4% of adults who had heard of genetic testing *received* a test.
- Familial risk was associated with increased testing, BUT only 49.5% of participants in the highest risk group had *heard* of testing, of those 14.8% had *discussed* with their physician, and 4.5% had *received* genetic testing.
- Somewhat more testing among individuals with a personal history of cancer.

Conclusions

- These nationally representative data provide estimates of the prevalence of familial cancer risk in the U.S.
 - 34 million US residents have a family history of these cancer syndromes.
- Information about genetic testing is not reaching many at higher risk of inherited cancer.
- Systematic need for interventions to improve collection of these data and counseling based on risk.