

Genetic counseling and testing in families with hereditary nonpolyposis colorectal cancer.

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BACKGROUND: Genetic testing to refine cancer risk is available. However, little is known about factors affecting the uptake of testing for the most common hereditary colon cancer, hereditary nonpolyposis colorectal cancer. This study investigated attitudes, intentions, and uptake of genetic testing within newly identified families with hereditary nonpolyposis colorectal cancer. **METHODS:** Cohort study conducted at the National Institutes of Health between April 15, 1996, and November 20, 1999. Data were collected through questionnaires before semistructured education sessions, individual counseling sessions, and the offer of genetic testing. **RESULTS:** Of the 111 eligible first-degree relatives, 51% chose to participate in education and individual counseling sessions. Participation was associated with greater numbers of first-degree relatives with cancer; no association was found between participation and personal history of cancer. Before education and individual counseling sessions, 64% of participants had heard little about genetic testing for cancers; however, most (97%) stated intentions to pursue testing. Fifty-one percent identified learning about their children's risks as the most important reason to consider testing. Thirty-nine percent identified the potential effect on their health insurance as the most important reason to not undergo testing. Of the 111 eligible first-degree relatives, 51% chose to undergo genetic testing. Participants' intentions to pursue genetic testing were significantly affected by concerns regarding the ability to handle the emotional aspects of testing and the psychosocial effect on family members. **CONCLUSIONS:** Genetic counseling and testing offers the potential to focus cancer screening resources in individuals truly at increased risk, thereby reducing mortality and morbidity. Fears of discrimination and concerns about psychological and psychosocial issues may present barriers to the use of current cancer prevention strategies, including genetic counseling and testing.

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