

**Genetic testing for hereditary colorectal cancer in children: Long-term psychological effects.**

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Children who carry a gene mutation for familial adenomatous polyposis are virtually certain to develop colorectal cancer without annual endoscopic screening and a colectomy when polyps appear. Predictive genetic testing can identify children who need regular surveillance. While the medical benefits of genetic testing are clear, the psychological effects have not been well studied. We evaluated the long-term psychological effects of genetic testing in 48 children and their parents. In each family, one parent was a known APC gene mutation carrier. Before genetic testing, and three times afterward, participants completed measures of psychological functioning, which, for children, included depression and anxiety symptoms, and behavior problems and competencies. Parents completed a measure of depression symptoms. Data were collected at 3-, 12-, and 23-55 months after disclosure. Twenty-two children tested positive; 26 children tested negative. Mean length of follow-up was 38 months. There were no clinically significant changes in mean psychological test scores in children or parents, regardless of the children's test results or the sex of the affected parent. However, the group of children who tested positive and had a mutation-positive sibling showed significant, but subclinical, increases in depression symptoms. Furthermore, several individual mutation-negative children with a positive sibling had clinical elevations in anxiety symptoms at one or more follow-up. Behavior problems declined for all groups, and behavior competence scores remained unchanged. We conclude that most children do not suffer clinically significant psychological distress after testing. However, because some children showed clinically significant anxiety symptoms, long-term psychological support should be available to those families with both mutation-positive and mutation-negative children, and with multiple mutation-positive children. Our findings should call for a multidisciplinary approach to genetic testing for children. Copyright 2002 Wiley-Liss, Inc.

PMID: 12494429 [PubMed - in process]