Intervention Strategies to Reduce Barriers to Colorectal Cancer Surveillance Among Members of Familial Adenomatous Polyposis (FAP) Families

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Methods of the Study
In order to generate discussion, moderator guides were created. The moderator guides are in a question/answer format to help the focus group moderator lead group discussions and elicit the desired information from the participants. Once separate moderator guides were completed for the parent and adolescent groups, telephone recruitment scripts for the two groups were drafted as a standardized method of recruiting research participants and to satisfy Institutional Review Board requirements. The moderator guides and telephone recruitment scripts will be used for a planned study once funding is obtained.

Aims of the Focus Groups
1) Discover obstacles to screening for people who are genetically at risk for colon cancer.
2) Find out what helps people overcome obstacles and get screened
3) Understand the different barriers for adults and adolescence.

The Study
Through a series of focus groups, this study is searching for barriers to colorectal cancer surveillance and hopes to identify intervention strategies for adults and adolescents who are at high risk for FAP and colorectal cancer. In this way, we hoped to identify important psychosocial causes for low adherence to cancer surveillance guidelines and develop effective intervention aimed at reducing morbidity and mortality. Possible barriers to screening include the following: procedure is painful, general fear of procedure, dislike for the preparation of the procedure, cost, and possible insurance problems. Participants will be given a questionnaire that will contain these barriers listed individually. Identifying barriers will help clinicians and counselors address important psychosocial issues associated with cancer surveillance adherence. The focus group findings will serve as pilot data to help secure NIH ROI funding to develop and test an intervention aimed at addressing surveillance behavior.

What is FAP?
FAP is characterized by the sporadic growth of polyps within the colon. Unremoved, these polyps will ultimately lead to colorectal cancer in all cases, and an increased risk for extracolonic cancer in other major organs in the body. The average age of polyp growth among individuals carrying the mutated gene is six years. Cancer surveillance procedures such as colonoscopies and sigmoidoscopies are used to detect early stages of polyps.

The Problem
Despite the clear benefits of regular colonoscopies, a recent study found low adherence to surveillance guidelines by at-risk FAP patients. Adherence was particularly low in adolescents, less than 5% of whom adhered to the surveillance guidelines (as reported by their parents) (Kinney, et al. unpublished data).