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

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Familial adenomatous polyposis (FAP) is inherited through autosomal dominant transmission; 50% of offspring inherit the disease-causing mutation. The syndrome is characterized by the sporadic growth of hundreds to thousands of polyps in the colon. Unremoved, these polyps will ultimately lead to colorectal cancer in virtually all cases. Gene mutation carriers also have an increased risk for extracolonic cancers. Despite the clear benefits of regular colonoscopies, a recent study conducted by Dr. Kinney and other Huntsman Cancer Institute investigators found disappointing low adherence to surveillance guidelines by FAP patients and their relatives. Less than 10% of adolescents were adhering to the surveillance guidelines. Understanding reasons for the low surveillance rates is important, because through regular screening colorectal cancer may be prevented. Cancer prevention can be accomplished through enhanced monitoring and prophylactic colectomy for individuals diagnosed with FAP.

Through a series of focus groups, an extension of the current telephone interview study was created to elicit information on potential intervention strategies to increase use of colorectal surveillance tests. These strategies, provided by participants, would identify methods of intervention tailored to adolescents. This information will help us develop and test interventions that increase adherence rates for cancer surveillance and ultimately reduce colorectal cancer-related mortality in young members of FAP families. 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.