Attitudes of Parents at risk of inheriting Li-Fraumeni Syndrome towards predictive genetic testing in their minor-aged children.

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Li-Fraumeni Syndrome (LFS) is a hereditary cancer syndrome which predisposes individuals to cancer beginning in childhood. These risks are spread across a lifetime, from early childhood to adulthood. Mutations in the p53 tumor suppressor gene are known to cause the majority of cases of LFS. The risk for early onset cancer in individuals with Li-Fraumeni Syndrome is high. Studies have shown that individuals with LFS have a 90% lifetime cancer risk. Children under 18 have up to a 15% chance of cancer development. Effectiveness of cancer screening and management in individuals with Li-Fraumeni Syndrome is unclear. Screening for LFS-associated cancers has not been shown to reduce mortality. Due to the lack of effective screening techniques for childhood cancers, institutions vary with regard to their policies on testing children for LFS. There are currently no national guidelines regarding predictive testing of children who are at risk of inheriting LFS. No studies have looked at parental attitudes towards predictive p53 genetic testing in their children. This was a cross-sectional pilot study aimed at describing these attitudes. We identified individuals whose children were at risk for inheriting p53 genetic mutations. These individuals were provided with surveys which included validated measures addressing attitudes and beliefs towards genetic testing. The questionnaire included qualitative and quantitative measures. Six individuals completed and returned the questionnaire with a response rate of 28.57%. In general, respondents agreed that parents should have the opportunity to obtain p53 genetic testing for their child. Parents vary in regard to their attitudes towards who should be involved in the decision making process and at what time and under what considerations testing should occur. Testing motivations cited most important by respondents included family history, planning for the future and health management. Concern for insurance genetic discrimination was cited as the most important “con” to genetic testing. Although limited by a poor response rate, this study can give health care practitioners insight into testing attitudes and beliefs of families considering pediatric genetic testing.