Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program
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Title: Assessment of a Video on Genome Testing Expectations and Results: Parent and Adolescent Views and Understanding

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Background: Return of results from genomic research raises issues about how best to help parents and adolescents understand genomic test results. Concerns about the return of results includes whether participants understand the limitations to testing, the possibility of secondary findings, and the risks and benefits of receiving positive and/or negative results. In this study we assess the views and understanding parents and adolescents have toward an audiovisual tool developed to explain the aforementioned topics required for the return of results prior to genomic testing.
Methods: The study consisted of two phases. In the first phase, adolescents and parent watched a video on genomic test expectations and results, and then completed a 14-item questionnaire assessing understanding of video content. Parent and adolescent responses were compared using a two-sided independent t-test and Fisher's exact tests. Additional t-tests compared adolescent responses between age, race, gender, and household income. In the second phase, ten healthy adolescents watched the same video from phase one and filled out a 16-item questionnaire afterwards geared toward assessing understanding of video content. Adolescents were then interviewed on their reactions to the video. Interview questions also covered areas of understanding that were shown to be lacking in adolescents compared to parents based on results from phase one of the study. All interviews were audio recorded and transcribed verbatim. Transcripts were coded and analyzed for major themes.
Results: Ninety-seven adolescent and parent pairs completed the phase one questionnaire. A two-sided independent t-test (CI 95%) showed significant difference in average overall correct responses between parents and adolescents ($p<0.001$). Further analyses using Fisher's exact tests (CI 95%) revealed eight questions with significant differences between adolescent and parent responses. There were no significant differences in adolescent responses based on age or gender, however significant differences were found when comparing race ($p<0.001$) and income ($p=0.014$). In phase 2 interviews, adolescents thought the video was informative, but some also raised concerns about its length. When asked about genomic testing, adolescents understood that testing could reveal information about their health risks and those of family members. The majority of adolescents understood basic genomic concepts, but struggled to explain many of them, including the meaning of positive and negative test results. Adolescent's recall of test utility from the video included healthcare changes including change in lifestyle factors and the use of medication.
Conclusions: Findings showed that adolescents had a harder time understanding the information provided in the video. Adolescents scored lower on the questionnaire than parents for all answers, and in the qualitative interviews, adolescents lacked confidence when describing key concepts described in the video they had just viewed. These dynamics were exacerbated among minority and low-income adolescents. Adolescent recall and responses might also be influenced by receiving this information for the first time in the video. Prior education might improve adolescent recall of this information, and repeated exposure to the video, from initial consent through the conclusion of genomic testing, might also improve recall and understanding.