IN THIS ISSUE

Engaging adolescents in genetics and genomics

https://doi.org/10.1038/s41436-018-0320-1 and https://doi.org/10.1038/s41436-018-0275-2

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As the utilization of exome and genome sequencing has broadened, the question of how to handle secondary findings has garnered a great deal of attention. When children and adolescents are the ones being tested, the topics of discussion have focused largely on the types of secondary findings that might be returned, potential implications of the findings, and protection of the child's future autonomy. Recent recommendations favor engaging adolescents in decisions about genomic sequencing and the return of results. However, as the authors of two articles in this issue assert, little is known about whether and how adolescents would like to participate in decisions about genomic testing or what adolescents consider important when choosing the test results they want—and do not want—to receive. It is also unclear which educational approaches are most effective for relaying information to adolescents about the benefits, risks, limitations, and implications of possible findings of genomic sequencing.

In the article entitled "Giving adolescents a voice: the types of genetic information adolescents choose to learn and why," Pervola et al. describe their exploration of whether and why adolescents want to participate in making decisions about genetic testing, and what matters to them as they consider which types of results to receive. The research team recruited 64 adolescent/parent dyads. The adolescents recruited lacked a clinical indication for genomic sequencing. The median age of participants was 15 years (range 13–17). Adolescents and parents were provided decision tools and information about genomic sequencing, including information about potential findings. Participants were then asked to make separate, independent decisions about the types of test results they wished to receive. Next, the adolescents and parents were brought together to discuss their choices and come to a consensus decision. Independently, 33 adolescents chose to learn all the results of genomic testing, while 31 chose to exclude some or all results. Of the 31 adolescents who chose independently to exclude results, 71% excluded results for untreatable conditions, 58% excluded results for conditions that could not be prevented, 35% excluded results for adult-onset conditions, and 29% excluded results related to carrier status. Key factors in the adolescents' decision-making included actionability, the potential psychological impact of the information, and an interest in the knowledge offered by the information. Fourteen of the 31 adolescents who initially chose to exclude certain results reconsidered after consulting with a parent and chose to receive more results from testing; another four chose to receive fewer results. The reasons given by adolescents for changing their decisions included noncoercive parental influence and improved understanding. Overall, 63 adolescents (98%) expressed an interest in being involved in making decisions: 53% wanted to decide independently, while 45% wanted to make decisions with their parent. Exerting autonomy and avoiding parental influence were important to the adolescents who wanted to make decisions independently; having a say was important to the adolescents who wanted to make decisions with their parents. The authors concluded that their findings are relevant to the development of policies and guidelines for the engagement of adolescents in decisions about genomic testing.

In an article entitled "Increasing genomic literacy among adolescents," Sabatello et al. tested two educational approaches to determine which one most improved adolescents' knowledge of genomic sequencing. The research team utilized an 11-minute animated video and a printed pamphlet, both of which had been tested in a previous study with adults. For this study, however, the pamphlet was edited to improve readability by adolescents. Forty-three participants, age 14–17 years, were enrolled. The mean age of participants was 15.3 years; 51.2% of participants were female; 53.5% identified as white, non-Hispanic; and 46.5% were from households with annual incomes less than $74,999. After a preintervention knowledge assessment, the adolescents were randomly assigned to watch the video ($n = 22$) or read the pamphlet ($n = 21$). Overall self-rated and objective knowledge of genomic sequencing increased significantly postintervention. No significant difference was observed between age or intervention groups except in the category of knowledge of limitations of genomic sequencing, which was significantly improved for the video group versus the pamphlet group. Twenty adolescents in each intervention group stated that they believed the information would aid decisions about participating in genomic research; 77% stated interest in participating in research and 88% stated interest in receiving results, with no significant difference between the intervention groups. Females, however, were significantly more likely than males, and 14- and 15-year-olds were significantly more likely than 16- and 17-year-olds to indicate an interest in receiving results. Additionally, although not significant, more participants in the video group than the pamphlet group stated that the material was easily understood and the amount of information provided was appropriate. The authors acknowledge that this study was limited by its small size but conclude that educational materials can increase genomic literacy among adolescents and that a video format may be superior to written materials. —*Raye Alford, News Editor*

Genetics in Medicine (2019) https://doi.org/10.1038/s41436-019-0474-5