

Teens knowing results of their cardiomyopathy genetic tests may improve family function

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Sharing the results of genetic testing for cardiomyopathy in adolescents ages 13-18 does not appear to cause emotional harm to families or

adversely impact family function or dynamics, according to new research published today in *Circulation: Genomic and Precision Medicine*, an American Heart Association journal.

Genetic testing for cardiomyopathy in symptomatic children has the potential to confirm a diagnosis, clarify prognosis, determine eligibility for disease-specific cardiomyopathy therapies and even inform risk for other [family](#) members. Genetic testing for asymptomatic adults and children also occurs after one of their [family members](#) receives positive cardiomyopathy genetic test results. While [genetic testing](#) can have significant medical and social implications for both children and their families, there is limited research on the psychological impact of cardiomyopathy genetic results and how the test results may affect family function and dynamics.

"As a medical geneticist caring for children with a personal or family history of cardiomyopathy, understanding how young people and their [parents](#) process the genetic test results and adjust after genetic testing are critically important," said Wendy K. Chung, M.D. Ph.D., senior author of the study, chief of clinical genetics and Kennedy Family Professor of Pediatrics and Medicine at Columbia University in New York City.

"Genetic testing for cardiomyopathy could help to save lives, yet also has the potential to have a major impact on young people by limiting their sports participation or socialization with peers and may increase feelings of vulnerability during formative teenage years."

To determine family function and dynamics after children and their families receive genetic testing results, Chung and colleagues used a 60-question survey distributed to members of the Children's Cardiomyopathy Foundation and seven additional North American sites in the Pediatric Cardiomyopathy Registry. The survey questions are based on problem solving, communication, roles in the family, affective responsiveness, affective involvement, behavior control and general

functioning. The questionnaire, known as the McMaster Family Assessment Device, measures an individual's perceptions of their family on a scale of one to four, with a four indicating the worst levels of family function. Following completion of genetic testing, parents and children took the survey. Additionally, adult participants were surveyed on their feelings about their child's genetic test results, and adolescents were surveyed on their feelings after receiving their own test results.

A total of 162 parent participants completed the survey; almost 60% of the respondents were female, and the average age of parents at the time of survey completion was 41.5 years. A total of 48 adolescent participants completed the survey, with an equal number of male and female respondents, average age of 16.7 years.

The researchers found that:

- A total of 91% of adolescent respondents with and without [cardiomyopathy](#) were glad to know their genetic testing results;
- Half of the parents responded they would prefer to receive the genetic test results in advance of their children receiving the results. Almost 41% of parents believed the child and parents should receive results at the same time; and,
- Nearly 71% of adolescents believed they should receive their genetic test results at the same time as their parents, while only about 16% believed their parents should receive the genetic test results first.

"With greater use of genetic information in medical care, it is important for clinicians to find ways to engage [young people](#) in this process so that they understand their test results and they can make positive changes that can improve their health," said Chung. "Understandably, some individuals experience [negative emotions](#) when they find out they have a genetic risk for a serious heart condition; however, their families appear

to function better than those whose test results were negative."

The study is limited by a modest sample size of people who were predominantly non-Hispanic white participants; therefore, the results cannot be generalized to all population groups. There may be important cultural differences in family dynamics and feelings about genetic test results in other racial and ethnic groups that could not be measured in this study.

Additionally, because most participants were enrolled in the survey retrospectively, the time between receiving genetic [test](#) results and completing the survey varied from a few months to a few years; therefore, memory recall may contribute to some adjusted or inaccurate perceptions. The researchers suggest future studies that can prospectively investigate the impact of genetic testing on families to better understand how time affects their experiences.

Provided by American Heart Association

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