

Assumptions, not data, dictate opinions about predictive genetic testing in youth

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Predictive genetic testing may be able to identify children's risk for developing common, treatable, and possibly preventable disorders.

Using this knowledge, doctors may be able to help at-risk children learn to manage their conditions by making healthy lifestyle changes. Test results may also be the motivation children need to take their health seriously as they grow older.

But critics of predictive genetic testing say test results may be psychologically harmful to children. However, these claims are rooted in [assumption](#), not evidence, says U-M researcher Beth A. Tarini, M.D., M.S., in a commentary available online today ahead of print the *Journal of Pediatric Psychology*.

Advocates challenge that testing during childhood could lead to early health interventions that might improve health.

Data supporting the claims of either side are sparse but fears about the negative effects of testing could hinder research that is needed to determine the exact benefits and harms resulting from sharing test results with children and parents, says

Tarini, a faculty member with the Child Health Evaluation and Research (CHEAR) Unit at the University of Michigan, is the commentary's lead author.

Conducting this much-needed research may be challenging, the study suggests, because existing professional guidelines warn that genetic testing has the potential to cause psychological and behavioral harm to children, who may be emotionally altered by knowing their results. However, these guidelines refer to the clinical use of genetic testing to diagnose severe, often untreatable disease. The guidelines do not address carefully controlled research on the effects of genetic testing which can provide a child's future risk of developing a common treatable disease, like diabetes. This type of testing is often referred to as predictive genetic testing.

Tarini worries that these guidelines will hamper research that could provide real answers to replace speculation.

"It's a classic catch-22," she says. "If people use these clinical guidelines as a means of discouraging research, then we will never know the truth and we will continue to be guided by speculation."

Genetic testing has the potential to identify individual's inherited vulnerabilities to diseases, some of which may be preventable. Because of these benefits, authors of the commentary suggest that predictive testing is likely to become part of pediatric medicine in the future. However, they worry that without research to guide physicians on the proper use of testing, it may be used and interpreted inappropriately.

There is concern that a child receiving information about the results of their testing may create unnecessary and regrettable psychological distress, alter their self-image or lead to health behaviors that will negatively impact their health, like taking unproven treatments, authors explain.

Children may also adopt a passive approach to their health, concluding that there is nothing that can be done about their condition, as it's "in

their genes."

In response to the claim that sharing test results may be psychologically damaging to children, the commentary authors cited a review of 17 articles focusing on the impact of genetic testing. Most found no significant difference between those who tested positive and those who tested negative in the areas of depression, anxiety, general psychological well-being, dispositional optimism and behavioral problems.

Because existing concerns remain speculative, Tarini suggests that continued research is necessary to determine if these proposed effects are rooted in fact or common assumption.

"A guiding principle of pediatric medicine is offering children the opportunity to be proactive in reducing their chance of developing a disease, a process genetic testing may contribute towards," suggests Tarini.

For example, overweight children could be tested to see if they have an elevated risk of developing diabetes, a factor that would greatly affect their continued care.

Results may also be used to create targeted prevention programs for unhealthy behaviors. Anti-smoking campaigns, for example, can be designed to focus on children with ADHD, who have an elevated risk of smoking initiation.

Based on their background and training in child development, pediatric psychologists should play an important role in research, the authors note.

"Pediatric psychologists are uniquely positioned to contribute to research in this area because of their understanding of how social, behavioral and developmental factors influence a child's health."

More information: [DOI: 10.1093/jpepsy/jsr040](https://doi.org/10.1093/jpepsy/jsr040)

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