What's your genetic destiny? More than half of parents want to know disease risks

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Credit: University of Michigan Health System

Would you want to know if you or your children had risk of hereditary cancer, a genetic risk for cardiovascular disease or carried the gene

associated with developing Alzheimer's disease - even if they were risks that wouldn't be relevant for possibly decades or didn't have a cure?

Using a small amount of blood or saliva, a technology called whole genome sequencing makes that possible - and more than half of parents said they'd not only be interested in the technology for themselves but for their children too, a new nationally-representative University of Michigan study shows.

Mothers as a group and parents whose youngest children had more than two health conditions had significantly more interest in predictive genetic testing for themselves and their youngest children while those with conservative political ideologies had considerably less interest. More than three- fourths of parents also showed the same interest in genome sequencing for themselves as they did for their kids.

The findings appear in this month's online-ahead-of-print issue of *Public Health Genomics*.

"As genome sequencing becomes faster and cheaper, we expect the technology to become used more frequently in clinics and the private market. We wanted to know what kind of factors influenced patient demand for this test, especially among parents," says senior author Beth Tarini, M.D., M.S., assistant professor of pediatrics at U-M's C.S. Mott Children's Hospital and researcher at the Child Health Evaluation and Research (CHEAR) Unit.

"Particularly fascinating was that parents' interest for having predictive genetic testing done for themselves reflected their interest in testing their children too - it appears to be a global decision for the family."

The study found that about 59 percent of the total population, including both parents and nonparents, were interested in genome sequencing.

Nearly 62 percent of parents said they'd be interested in the complete DNA read for themselves and 58 percent of parents were interested for their children.

Planning to have a child in the next five years was also significantly associated with greater interest in genome sequencing among adults overall but not significant among current parents. Authors speculate this could be because parents who have already had a healthy child may have "minds at ease concerning their own genetic makeup" compared to nonparents.

Whole genome sequencing is a laboratory process that examines a person's DNA makeup in order to provide information about the risk for developing diseases in the future, as well as to diagnose active symptoms or diseases. Currently, the technology is most commonly used to find a medical cause for patients who already have symptoms for an undiagnosed health condition.

While sequencing could reveal risk of a handful of rare and preventable diseases, authors note there is concern for how accurately the information would be interpreted and how useful it will actually be for patients.

"It's a test that gives you a lot of data but the devil is in the details," Tarini says. "First, interpreting the data is challenging because we are not sure what all of the data means. Second, even if you can interpret the data then you may not know what to do with the interpretation. Perhaps you learn you have a slightly higher risk of getting prostate cancer or diabetes - neither of which is for certain or in the near future. Now what?"

Ethical questions abound too - privacy for example. Parents may be interested in testing their children and learn risks of diseases that

wouldn't affect them until they were adults, such as breast cancer. These decisions could be deferred until the child is old enough to participate in them.

"We want our patients to be active participants in their health; however, the value of genome sequencing in helping individuals understand their disease risks is still controversial, especially for children," says lead author Daniel Dodson, a University of Michigan medical student.

"We hope our data will help clinicians both educate their patients regarding this technology, and partner with their patients in making well-informed health decisions."

More information: "Parent and Public Interest in Whole-Genome Sequencing," *Public Health Genomics*, online ahead of print March, 2015.

Provided by University of Michigan Health System