Knowledge of genetic risks from personal DNA tests may not help in changing behavior

23andMe, which sells a direct-to-consumer personal genetic test, sees a future where its home kit is easily available at every local pharmacy, as a means for people to learn their own personal genetic risks and use the information to improve their health. Currently, the kit provides carrier status for 25 conditions but the company is looking to add more information and may soon be available in the national chain Walgreens. But as it expands, is the data 23andMe is providing helping anyone?

Beyond 23and Me, the field of genetic testing as a whole has grown exponentially in the past few years, with tests being offered to the consumer, both directly and through a physician. From screening for genes that could convey an increased risk of heart disease or Alzheimer's, to tests that promise to help you build a better diet and become a better athlete, the myriad of choices available to consumers is growing by the day.

While many in the science and medical communities have question the ethics of providing sensitive information direct to consumer, it might be more pertinent to ask—is all this new genetic information, either from direct to consumer tests or from a physician or counselor, actually having the expected effect of influencing our behavior or habits?

The answer, at least according one recent systematic analysis published in the *British Medical Journal* yesterday is no. The group of researchers from the University of Cambridge and Imperial College in the United Kingdom analyzed results from 18 studies that looked at changes in seven behavioral outcomes including diet and smoking cessation when patients were told the results of genetic tests for risk of diseases that could be altered by changing their behaviors.

The result? They found no change either the behaviors or motivation to change behaviors in any of the cases. With the caveat that the data analyzed was not of the highest quality, the researchers concluded that communicating the results of genetic tests was unlikely to change behavior and that the expectations of the 'era of personalized medicine' may need to be tempered.

Experts contacted by the Genetic Expert News Service (GENeS) broadly agreed with the findings of the study, but also pointed out a few drawbacks which may be useful to design and interpret future studies of this nature. Robert Nussbaum, a professor and chief of the division of medical genetics at the University of California, San Francisco noted:

> The conclusion of this paper is exactly what I would expect when the kinds of genetic risks being communicated are very modest. Tests for common SNPs that alter odds ratios for disease by small amounts have low predictive value, and so I am not surprised that the results of such tests have little impact on behavior.

Brian Zikmund-Fisher, an associate professor of health behavior and health education at University of Michigan said, “the absence of effect shown in this meta-analysis is not surprising: the people most likely to act on genetic information are few in number and hence we tend not to find effects on average.”

Cecile Janssens, a Professor of Epidemiology at Emory University agreed, noting:

> common diseases are polygenic: they are caused by complex interactions between multiple genetic and non-genetic factors, and the impact of each single variant is limited. When individuals are tested for a single genetic variant, which was done in 12 of the 18 studies reviewed, they might learn that their risk of disease increases from, say, 10% to 12%. Such small increases in risk are not expected to increase motivation, definitely not for behaviors that are difficult to change. It is therefore not surprising that randomized trials failed to show a significant impact.

However, uniformly all of the experts highlighted that one of the major drawbacks of the review was that it considered all genetic tests to be equal. Testing for a gene variant that would change the risk of disease significantly is more likely to have an impact on behavior according to Zikmund-Fisher, citing the example of the APOE4 gene:

> The main limitation of this finding is the type of meta-analysis carried out in the study does not take into account the degree that having the variant changes the patient’s risk of disease. Take APOE, the gene related to Alzheimer’s disease examined in one of the papers in the review. APOE has several variants. APOE3 is most common, and people who have two copies of APOE3 face average risk. Having one copy of APOE4 (rare) increases the risk of Alzheimer’s disease by 2-3 times, while having two copies of APOE4 (much rarer) increases it 15 fold. People receiving information that they have 2 copies of APOE4 should be far more motivated to act than people receiving information that they have only one copy.

Cecile Janssens made a similar observation:

> A weakness of the review is that it gives the suggestion that all genetic tests are equal. The authors pooled the results of small studies by performing separate meta-analyses for diet, smoking cessation and physical activity, because they consider that these behaviors are different. But they ignored differences between the genetic tests. For example, among the seven studies that investigated the role of genetic testing on diet: one study tested the *APOE* gene among people with a family history of Alzheimer’s disease; one study tested the *FTO* gene for obesity risk in students; and one study tested multiple type 2 diabetes genes in people who were overweight or obese. Altogether, the seven studies investigated seven different genetic tests in five different populations to predict the risk of six different diseases. Evidently, combining them in one meta-analysis makes no sense.

The main takeaway here is that most genetic tests are unlikely to introduce a change in behavior, but in the right situations, could be a useful tool that may alert you to an important medical condition that can be

prevented. As Zikmund-Fisher puts it, “[the study] simply suggests that communicating genetic risk will likely be very useful to a small subset of patients rather than moderately useful to everyone.”

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