Commentary

Does genomic risk information motivate people to change their behavior?

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Abstract

The recent flood of information about new gene variants associated with chronic disease risk from genome-wide association studies has understandably led to enthusiasm that genetic discoveries could reduce disease burdens and increase the availability of direct-to-consumer tests offering risk information. However, we suggest caution: if it is to be any benefit to health, genetic risk information needs to prompt individuals to pursue risk-reduction behaviors, yet early evidence suggests that genetic risk may not be an effective motivator of behavior change. It is not clear how genetic information will inform risk-based behavioral intervention, or what harms might occur. Research is needed that examines the behavioral consequences of genetic risk knowledge in the context of other motivators and social conditions, as well as research that determines the subgroups of people most likely to be motivated, in order to inform policy decisions about emerging genetic susceptibility tests. Without such research, it will not be possible to determine the appropriate health care uses for such tests, the impact on health care resources from consumer-initiated testing, or the criteria for truthful advertising of direct-to-consumer tests.

For families with rare, highly penetrant genetic conditions, genome medicine is already a reality, with genetic tests that can identify the family members at high risk of disease. The rationale for testing is clear: it saves lives in families with conditions such as multiple endocrine neoplasia type 2, hereditary breast ovarian cancer syndrome and familial hypercholesterolemia by directing the use of prophylactic surgery, intensive screening strategies and specific treatment regimens. With these successes in mind, many people reasonably hope that similar benefits can be achieved on a population level by screening for more common genetic variants associated with disease risk.

The rapidly expanding number of known risk variants following from the dramatic success of genome-wide association studies [1] has fueled this vision of 'personalized medicine'. The logic is that identification of even modestly increased risks for common diseases enables providers to make personalized recommendations for screening and risk reduction. This assumes that genetic risk information will motivate behavior, because the greatest gains in prevention for common complex diseases will come from lifestyle improvements, such as smoking cessation for heart disease and lung cancer risk reduction, diet and exercise changes for diabetes and cancer risk reduction, and adherence to recommended screening guidelines.

But this vision of individualized genome medicine must be approached with caution. Most variants emerging from gene-disease association studies have very small effect sizes,

often with odds ratios of 1.5 or less [2,3], confirming that susceptibility to common chronic disease reflects a complex interaction between many different genes and the environment. Despite an increasing number of direct-to-consumer tests offering information about common disease susceptibilities, risk information of this sort may be most useful as an adjunct to current risk assessment, refining rather than replacing other methods of risk stratification [4]. It is also unclear whether most behavioral interventions can or should be individualized for people at moderately increased risk of disease. Aggressive prevention measures, such as prophylactic surgery, would be ethically and socially unacceptable for people with moderately increased risk, whereas many behaviors, such as smoking cessation and regular exercise, reduce risk for many diseases at all levels of risk [5].

Of most concern is the fact that we lack evidence that individualized risk information is an effective motivator of behavioral change. There are only a few studies on this issue, and results have been mixed to weak, with the most convincing evidence suggesting a link between genetic feedback and adherence to cancer screening [6]. Studies examining the potential of genetic feedback as a motivator of smoking cessation have shown neither large nor lasting impacts on behavior [7]. Optimal communication to patients of genomic risk is also not well understood and is an important area of study because achieving behavioral outcomes may be crucially dependent on how risk is conveyed [8].

Yet genetic risk information is likely to motivate some people in some circumstances for some behaviors; appropriate policy requires a further understanding of this motivation. For this we need high-quality data on the behavioral consequences of genomic risk information, giving critical attention to identifying settings in which it has the best potential to improve health outcomes. There are many robust theories of behavior change from the social and behavioral sciences that can guide research. An ecological model - one that includes the contributions of individual, family, community, institutions and society to behavior - may be the most comprehensive, because genes are shared by families and interaction with the media and health care system are often steps on a journey to genetic testing [9]. Models of individual decision-making about health behaviors provide starting points from which to explore individual reactions to knowledge of genomic risk [6,10,11,12].

For genomic prevention, the best results will come when genomic risk stratification can inform a prevention program that is specific to a particular risk group. For example, people at increased risk for melanoma are likely to benefit from periodic skin examination to identify potential early melanomas. The use of genetic risk information is likely to be persuasive for both patients and physicians. As we identify and evaluate such opportunities, we need to hold genomic risk information to the test of comparative effectiveness [13]: for example, is a DNA-based test to identify increased risk for melanoma better than the 'simpler' genomic test of identifying individuals with pale skin prone to freckling [14], or than other commonly used methods of risk assessment, such as family history?

By contrast, when lifestyle measures have universal value, personalized prevention is likely to have more to do with social circumstances than with genetic risk: a person living in a homeless shelter has much less access to conventional tobacco cessation programs than a hospital employee, and a person who has a long commute to work may find it difficult to exercise. In these cases, policy or environmental measures - free tailored counseling programs or workplace exercise space - are likely to offer more benefit than genomic risk information. Indeed, if the genomic era brings an increased emphasis on prevention, it may underscore the importance of risk-independent public health messages as a means to help improve the health of people most in need.

Genetic risk information seems to be associated with little distress or anxiety [11], although this also deserves further study. Nevertheless, it may be reasonable to assume that the psychological harms of genetic risk information are minimal, at least for people who seek such information. How concerned should we be, then, that many direct-to-consumer genetic risk profiles are now on the market? The cautions guiding health care uses of genetic testing are not necessarily the same as those guiding non-medical uses. Health care providers and funders have a responsibility to use tests with proven health value - a standard not yet achieved for genetic risk information intended to motivate healthy behaviors. But a consumer product needs merely to be safe.

For example, a manufacturer of exercise equipment does not need to prove it will improve health outcomes before marketing it; the equipment need only comply with manufacturing standards, and the onus of using it for health improvement is on the consumer. By similar reasoning, in the absence of known potential harm, consumer access to risk information that might, or might not, motivate healthy behavior can be justified. Yet even here, caution is in order. Consumers may understandably bring genetic test results to their physician, potentially generating a cascade of tests and procedures that would place inappropriate demands on an already burdened health care system [15,16].

We currently lack the knowledge to define when or how genetic risk information might motivate healthy behavior. Lacking that knowledge, we are unable to define appropriate health care uses, impacts on health care resources of consumer tests or parameters for truthful advertising of direct-to-consumer tests. Identifying the settings in which genomic risk can motivate healthy behavior, and perhaps the individuals most likely to respond to such information, is an important policy concern.

Competing interests

The authors declare that they have no competing interests.

Author contributions

NBH wrote the first and final drafts of this article; WB and DB contributed to the conception, design and critical revision of the article for important intellectual content.

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