

Comment

KNOW YOUR GENES. THE MARKETING OF DIRECT-TO-CONSUMER GENETIC TESTING

Predictive or preposterous? The marketing of DTC genetic testing

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ABSTRACT: Direct-to-consumer (DTC) genetic testing has generated a great deal of social controversy. While the degree to which DTC testing actually causes harm remains uncertain, there is a consensus that the information provided by these companies should be accurate. Unfortunately, this is often not the case. Indeed, there are misrepresentations associated with all forms of testing, be it for superficial cosmetic services, athletic ability or disease predisposition. Countering this phenomenon will require a wide range of actions, including the use of formal regulatory mechanisms, the education of primary healthcare providers (in order to give them the tools necessary to advise patients and respond to questions) and more aggressive action by the genetic research community.

Introduction

Direct-to-consumer genetic testing companies continue to receive a great deal of attention, by both policymakers¹⁻³ and the popular press. And while it remains unclear if there is a strong public demand for these services,⁴ the industry continues to grow.⁵ As a result of this growth, the marketing associated with these companies has emerged as an important and pervasive source of information about the nature and value of genetic tests.

Unfortunately, the information provided by these companies is far from ideal. The material is uniformly promotional in nature, often exaggerating benefits and downplaying risks.⁶ To date, much of the policy debate associated with DTC testing has focused on the companies that offer health and lifestyle testing. But, as outlined below, misrepresentations pervade the entire industry, regardless of the nature of the genetic test being offered. Indeed, the claims made by DTC testing companies can be placed along a continuum, from those that are scientifically ridiculous to those that are relatively scientifically accurate but for which the health value and limitations are misrepresented. Science communication strategies aimed at correcting the scientific inaccuracies associated with DTC genetic testing need to tackle the breadth of services provided. All have the potential to fuel (and simultaneously feed off) popular misrepresentations about the role and power of genetics in our lives, be that in the context of disease predisposition, our athletic abilities or whom we are likely to love.

The clearly preposterous

First, there are the genetic testing services that are almost certainly scams.⁷ These tests have no real foundation in solid science. These are the tests that are offered for everything from matchmaking to the development of individualized perfume to the provision of diet advice. For example, a company called ScientificMatch.com promises to use “your DNA to maximize the chances of finding chemistry – actual, physical chemistry – with your matches.”⁸ The company website explains that there are numerous benefits to “scientific matching”, including an increased chance that you will enjoy your partner’s smell, increased rates of fertility, a lower chance of cheating, more orgasms for women, and, naturally (and somewhat redundantly given the claim about orgasms), a more satisfying sex life.⁸

Another company, called My DNA Fragrance, is based on the idea that it can develop a perfume based on your unique genetic profile.⁹ Other DTC websites market a variety of cosmetic services. SkinDNA claims that it has a “DNA-based laboratory test that – for the first time ever – unlocks the secrets to Ageless skin, by harnessing the power of the body’s unique genetic blueprint.”¹⁰ The information from the DTC test can be used, or so the marketing alleges, “as a personal guide for building a complete, custom tailored skincare regimen.”¹⁰ And many companies and individuals have sought to exploit the public interest in dieting – a huge and profitable industry – by offering enumerable books and products that claim to be able to help individuals lose weight through genetics. The website for the Apo E Gene Diet states that it “brings leading-edge genetic science, genomics, DNA testing, and nutritional science together with the optimal Mind-Body-Spirit plan” in order to use the “individual’s genetic recipe” in order to provide a “customized dietary and exercise plan.”¹¹

While almost all of the claims made by these DTC testing companies are scientifically ridiculous, there are often threads of truth to the basic *ideas*, if not the proposed applications, behind their marketing pitches. For example, there are a few studies that have suggested a correlation between particular genes and variation in sexual behaviour (e.g., one study claims that “individual differences in sexual behavior are likely partially mediated by individual genetic variation in genes coding for motivation and reward in the brain”¹²). And these snippets of scientific legitimacy are often presented in the popular press in a manner that makes the relevant research seem more definitive and to have more far reaching implications than is the scientific reality – thus we get headlines like: “Thrill-Seeking Gene Can Lead to More Sex Partners”¹³ and “Like to Sleep Around? Blame Your Genes”.¹⁴ These popular culture portrayals help to stimulate the public expectations that make these companies viable.

But, of course, it would be folly to extrapolate that a genetic test can provide anything near a conclusive prediction about something as socially convoluted as fidelity. Nor can they provide truly meaningful insight into that most complex of all human emotions, love.

Even in the context of diet, an area where one might expect genetics to play an identifiable and significant role, the current state of the science lags far behind the DTC marketing claims.¹⁵ Genetics clearly accounts for some of the variation in how we metabolize food and has an influence on the risk of obesity,^{16,17} but not to the degree and in the simplistic manner so often portrayed by those selling genetic-based diet plans (e.g., one popular genetically enhanced dieting approach claims that we each have a broad diet genotype with intriguing names like “the warrior”, “the hunter”, and “the teacher”¹⁸). Indeed, the gene that is currently viewed to be the most predictive of the genetic variations associated with obesity, the FTO gene, is not terribly prognostic. As noted in a recent literature review: “The effect of FTO SNPs on BMI is modest, with those individuals homozygous for the risk allele weighing, on average, 3 kg more than those homozygous for the protective allele” (p. 267).¹⁷

More importantly, it is unclear what, if any, genetic variations these DTC companies are actually testing for. The DTC information provided by the companies that fall into my “preposterous” category rarely provides information on the specific genetic variations that are to be analyzed. Rather, they are simply trading on the excitement associated with the field of genetics to make it sound like their products are scientifically legitimate. The matchmaking website, for example, simply asks customers to use their collection kit to send in a swab of DNA. There is no information about what they are looking for (to be fair, there is a reference to “immune system genes,” but these seem unlikely to have much to do with improved sex, orgasms and fidelity). Have they found a highly predictive love gene or is this simply about body odor? (The latter is a big theme on ScientificMatch.com.) How, as their website claims, will their computers use the DNA to make a match?

The marginally pertinent

The second category of tests includes those that are used to look for genes that have an actual scientifically identified biological function. The genes are real. The tests are real. As such, these DTC services are arguably more scientifically legitimate than the tests noted above in that these companies are offering a service that can (in theory) detect the presence of the gene they claim to be testing for. The distortion of the truth lies not in the nature of the test or what is being tested for, but in the relevance of a genetic test result.

The growth in tests for “athletic ability” is the best example of this kind of marketing misrepresentation. Several companies are currently offering a testing service for the identification of

variants of the *ACTN3* gene.¹⁹ This gene has been called the “speed gene” due to the fact that a particular variant has been found to be more common in elite athletes involved in speed and power sports (e.g., sprinting and football). But the relevance of the gene – about 30% of the population carries the two copies of the variant associated with speed²⁰ – to actual “athletic ability” is greatly exaggerated by DTC companies. The president of operations for Atlas Sports Genetics, for example, has been quoted as saying: “Our goal is to help people become the athlete they were born to be.”²¹ And the brochure from another DTC company claims their test will “help determine if you have the potential for Olympic size success.”²² And “one company markets a test based on this association as a parenting tool for helping to assure that children don’t ‘grow against’ their inborn talents” (p. 459).²³

While this gene *is* related to the regulation of fast-twitch muscle fibers, it is wrong to imply that it is a test for athletic ability, a complex, socially constructed and multi-factorial concept, or that it can provide anything close to a definitive conclusion about future speed abilities. Athletes who do not have the alleged speed gene have made it to the Olympics in speed/power sports and many millions who do have the favoured genetic allotment have languished in mediocrity. As nicely summarized by Brooks and Tarini: “Such testing promotes a reductionist view of athletic performance among parents and coaches. Athletic performance is a multifactorial trait of which genetics is but 1 factor. Although researchers continue to investigate hundreds of genes for potential effects on sports performance, it is estimated that the *ACTN3* gene accounts for only 2% of the variance in muscle performance” (p. 1033).²⁴

The vaguely predictive

Finally, there are the companies that have been the focus of most of the policy debates and regulatory machinations.^{2,25} These are the companies that utilize the most recent sequencing technologies to test for susceptibility to hundreds of diseases and traits. These companies, such as 23andMe²⁶ and Navigenics,²⁷ are often quite sophisticated and present, directly to consumers, a great deal of genetic risk information. And this information is often linked to the very latest peer reviewed literature. The services are relatively cheap – as of writing, 23andMe was charging just \$99 – and the results range from the relatively benign (e.g., predisposition to a particular kind of ear wax) to the serious (e.g., genetic risk to prostate cancer or Alzheimer’s disease).

But even with these DTC companies there are problems with the marketing claims, albeit of a less overt variety than those found on the websites for the more preposterous products. The most problematic (and, I would argue, scientifically misleading) message emanating from these companies is the idea that the provided genetic information will be of profound value to your health and that unique preventive action can be taken. The underlying message from these companies is that the risk information will allow you to personalize your healthcare decisions and take preventive steps to avoid the development of serious diseases. But, in fact, the vast majority of the predispositions revealed by these DTC companies are only marginally predictive (e.g., an increase of 1% to 1.6% for cardiovascular disease²⁸), especially when compared to the risks associated with things like smoking, poor diet and obesity. In addition, other than the usual and well-known preventative strategies – exercise, eating fruits and vegetables, *not* smoking, etc. – there is very little we can do in response to revealed genetic predispositions, particularly in the context of common chronic diseases.²⁹ And there is also little evidence that knowledge of genetic risk will motivate healthy behaviour change,³⁰ which is the reason why, or so the DTC websites tell us, we should get tested. In other words, finding out that you are at an 0.6% increased risk for heart disease is unlikely to get you to start avoiding junk food or take the stairs instead of the elevator.

The bottom line: even the most sophisticated genetic testing companies cannot live up to many, if not most, of the claims that permeate DTC marketing, a point that has been noted in several policy reports.¹ To make matters worse, research has found that the way in which information is provided on the websites of the DTC companies is far from ideal or complete. A study of DTC websites done by Einsiedel & Geransar found that, in general, the websites “provide limited, vague or inaccurate information about the causes of a disease” and “emphasize the risks of ignorance (by not availing oneself of a genetic test)” and play on “themes of individual control over social, emotional or physical lives” (p. 354).⁶ To add to this dilemma, it has been noted that the results provided by some DTC genetic testing are often widely inaccurate.^{1,31,32} While a discussion of the problems associated with the technical accuracy of DTC testing is beyond the scope of this commentary, the fact that test results are inaccurate and inconsistent makes the promotionally motivated assertions about health benefits all the more tenuous.

Future steps

The grand (and unsupportable) claims of benefits associated with DTC marketing are, of course, primarily the result of a desire to generate profit. Many of these companies, such as those linked to skin care and matchmaking, are simply leveraging the excitement and popular culture prominence of genetic research to sell products. The use of the language of legitimate science to market products of questionable value is hardly new. It seems to occur whenever a new field of science gains notoriety – be it electricity, magnetism, radioactivity, nanotechnology or stem cells (I have previously labeled this phenomenon “scienceploitation” – the exploitation of legitimate fields of science and, too often, patients and the general public, for profit and personal gain³³).

To be fair, my above categorization of DTC companies is a bit too rough. Some companies, for example, offer tests that could fall into all three of my categories.²⁰ And some companies test for mutations that are highly predictive of future disease (a reality that raises other social issues). But, from the perspective of science communication, the point is the degree to which misinformation regarding the science and value of genetic testing pervades the entire industry – it can be found in the marketing of both the most outlandish skin care services and the most sophisticated of the health-focused DTC companies.

While the desire for profit lies at the heart of this phenomenon, it must be recognized that it builds on the hype about the health value of genetic testing that often flows from the research community,^{15,29} the representations of hype that appear in the media and throughout popular culture,³⁴ and the public expectations that are fueled by this hype. But regardless of the source, there seems little doubt that misrepresentations are common and that steps should be taken to improve this science communication predicament.

Indeed, the need to ensure the provision of accurate information is, arguably, one of the issues on which all of the policy reports that have considered DTC testing seem to agree.^{1,15} In 2010, for example, the US Government’s Secretary’s Advisory Committee on Genetics, Health, and Society report on DTC testing notes that “providing accurate and balanced information is a key concept in the regulation of DTC advertising.”³² And recently the American Bar Association passed a resolution on the marketing of DTC genetic testing asserting, *inter alia*, that steps should be taken to ensure that the “claims made and information provided by direct-to-consumer medical genetic testing companies are truthful, accurate, and not misleading.”³⁵

Despite this emerging consensus, it is important to note there is an ongoing debate about the degree to which DTC testing does and could cause individual and social harm.³⁶ For instance, a recent review by McBride, et al., concluded that, “existing data, although insufficient, suggest that DTC genetic tests have not resulted in negative outcomes on consumers or health service delivery” (p.441).³⁷ But regardless of the degree of measurable harm caused by misinformation (I am unaware of research that has explored that impact of misleading marketing in the context of DTC genetic testing), it seems axiomatic that the provision of misinformation through marketing strategies or otherwise can’t be a constructive trend. It seems likely to contribute to broader public confusion about the value and benefits of genetic testing (as noted above, it is too often the case that marketing claims end up being reported in the popular press as scientific fact) and erode the potential for consumers to make informed decisions about testing. In addition, the circulation of exaggerated claims of benefit, which will inevitably go unmet, will do little for the long-term legitimacy of the field.

Countering this phenomenon will require a range of actions including the use of formal regulatory mechanisms (e.g., where available, the utilization of regional “truth-in-advertising” laws^{2,35,38}), the education of primary healthcare providers (in order to give them the tools necessary to advise patients and respond to questions) and more aggressive action by the genetic research community.²⁰ The latter strategy seems particularly important. As noted, much of the fuel for the exaggerated claims flows from the research community. Scientists need to embrace and encourage more realistic depictions of genetics and take active steps to counter misleading claims,²⁹ be they made by the purveyors of DTC genetic tests or by their colleagues.

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