

The Use and Misuse of Genetic Data

by
Gary E. Marchant

Comrades, while physics and chemistry remain pure sciences, genetics is the bastard child of the decadent capitalist society.

—T.D. LYSENKO

In the recent Supreme Court decision overturning patents on naturally occurring gene sequences (*Ass'n Molecular Pathology v. Myriad Genetics*), Justice Scalia filed an intriguing concurrence in which he joined in the decision except for the parts “going into fine details of molecular biology. I am unable to affirm those details on my own knowledge or even my own belief.” Of course, understanding the specifics of genetic testing was critical to delineate the appropriate bounds of patents for protecting genetic data in that case. So Justice Scalia’s inability or refusal to engage with that knowledge demonstrates the challenges that legal and other decision makers confront in our era, when genetic data are increasingly applied in a growing range of medical, forensic, legal, and other applications. Going back at least to the time of T. D. Lysenko, Stalin’s agricultural minister who overrode modern genetic knowledge with unsupported scientific theories more compatible with his political ideology, genetic information has been prone to hype, exaggeration, fraud, and distortion by charlatans using the science for their own agendas. Discerning valid from invalid uses of genetic information is therefore critical for law, government, consumers, and businesses.

In this regard, the applications of genetics can be grouped into three general categories. The first includes well-established, clearly beneficial, and relatively noncontroversial applications. Examples include testing for the BRCA gene to predict the risk of cancer in women with a family history of breast cancer, DNA profiling to test matches between criminal suspects and forensic samples left at crime scenes, and DNA testing to prove or disprove paternity. This first category of accepted uses of genetics, slow to expand for many years, is now growing rapidly.

The second category involves emerging uses of genetics that are borderline, the subject of legitimate debate among experts as to their validity and utility. In many cases, the evidentiary support for such tests is still developing, so their acceptance is shifting. Although some (or, in some cases, most) experts think some such tests may be premature or ill-advised at this time, they usually do not dismiss their potential in the future. In addition, there are experts (even if only a minority) who advocate such testing now. Examples in this second category include pharmacogenetic testing for variations in the response to drugs such as warfarin and Plavix, identifying individuals whose poor early environments put them at an increased risk of criminality because of their monoamine oxidase A (MAOA) genetic variants, and sequencing the whole genome of asymptomatic individuals.

The third category of genetic data, the primary focus of this article, contains applications that fall under the definition of pseudoscience. Given the implications and growing power of genetic information, it may not be surprising that genetics has been the subject of hype, exaggeration, and deception, be it for commercial,

ideological, or personal reasons. Thus, we must identify invalid or dubious applications of genetics, both to prevent contaminating our perceptions of legitimate uses and to provide precedents to expose fraudsters who seek to exploit genetics' growing popularity. This article identifies such applications and groups them into the categories of racial, criminal, behavioral, medical, and product applications of genetics.

The Sordid History of Race and Genetics

There is a centuries-old history of misusing heredity, and more recently genetics, to support racist beliefs. From the biological determinism that classified and stigmatized races in the 18th and 19th centuries (documented in Stephen Jay Gould's *The Mismeasure of Man*) through the eugenics movement in the United States in the early 20th century and in Nazi Germany to more recent assertions, such as those in *The Bell Curve*, the consistent theme in the claims of racial differences is that they come more from preexisting political and racial beliefs of the proponents than from scientific data.

Unable to learn the lessons of these prior abuses, modern actors continue to play the genetic race card. In 2012, a member of the Hungarian parliament from the Far Right Jobbik Party proclaimed his ethnic purity based on the absence from his genome of variants allegedly attributable to Italian or Jewish ancestry. His claim was condemned by the president of the European Society of Human Genetics, who criticized it as both scientifically and ethically indefensible and a "scandalous abuse of a technology that was developed to help the sick, rather than to promote hatred." In 2007, Nobel Prize-winning geneticist James Watson got into hot water when he stated that he was "inherently gloomy about the prospect of Africa" because "all our social policies are based on the fact that their intelligence is the same as ours—whereas all the testing says not really." In response to the controversy that followed, Watson apologized for his statement and acknowledged that "[t]here is no scientific basis for such a belief."

It's Criminal

Genetics have long played an important role in the justice system, going back to Justice Oliver Wendell Holmes's opinion in *Buck v. Bell* that "three generations of imbeciles are enough." One of the notorious abuses of genetics in criminal law was the claim in the 1960s and 1970s that men with the XYY genotype were more prone to aggression than men with the more common XY genotype. Subsequent studies demonstrated that this correlation was an artifact of the studies' methods, but this episode opened the door to the use of genetic information in criminal cases. In an example that many experts think goes too far, the State of Connecticut recently announced that it was testing the genes of Adam Lanza, the deceased killer who massacred schoolchildren in Newtown, Connecticut, in December 2012.

Judges can also be prone to the spurious construction of genetics. In a recent case (*U.S. v. Cassey*), the Second Circuit Court of Appeals overturned the district court judge's decision to impose a criminal penalty for a child pornographer that exceeded the plea agreement, based on the judge's supposition that 50 years from now the defendant's criminal conduct would likely be discovered to be caused by "a gene you were born with. And it's not a gene you can get rid of." The judge continued that therapy would not succeed, because "you can't get rid of it. You are what you're born with. And that's the only explanation for what I see here."

Behavioral Problems

There has been a never-ending series of alleged discoveries of genes for complex human behaviors, such as the anxiety gene, the infidelity gene, the intelligence gene, the free-thinking gene, the religiosity gene, the shopping gene, the humility gene, the novelty-seeking gene, the perfectionist gene, the bad-driving gene, the cleanliness gene, the wimpiness gene, and many others. There are, of course, no single genes "for" any of these complex human behaviors. At most there are genes that may influence or perhaps are merely

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correlated with specific behavioral traits. Any human behavior is likely the result of a complex interaction between many genes and the environment. Eric Lander, one of the nation's leading genetic researchers, quoted from a European news report that illustrates the silliness of such genetically deterministic perspectives on behavior:

“These findings promise to change the way we live,” says Dr. Manuel Paranto of the Lisbon Research Institute in Portugal. “When a child is born, we will give the parents a detailed analysis of its genetic makeup so they will know what kind of education to provide. The child will know from birth whether he is more suited to slim redheads or buxom brunettes, intellectuals or homebodies, to avoid romantic heartbreak. Ultimately, things like divorce will become extinct as people realize what kind of people they should marry.”

These exaggerated claims for behavioral genes are not just reported in the media: they have also been directly marketed to consumers. For example, the Singapore-based My Gene Profile offered to parents for \$1,397 its “Inborn Talent Genetic Test” that allegedly tested 40 gene variants in children including the “optimism gene, risk taking gene, sociable gene, persistence gene, . . . memory gene, intelligence gene, . . . [and] propensity for teenage romance gene.” The company's marketing materials promised, “Remember you are getting a blueprint of your

child's inborn talent. You get to know what your child's talents are, how they behave.” The specific genes tested were never identified, and the company has now apparently gone out of business.

Medical Mischief

Genetics is likely to be most useful in the medical context. At the same time, many bizarre claims and proposals for medical genetics have been made over the years. One of the strangest came from double-Nobel Prize winner Linus Pauling in the 1960s. He called for legislation that required compulsory testing for “defective genes” before marriage. The results had to be publicly disclosed, perhaps by tattooing them on the forehead of every young person, so that potential mates could determine on first meeting the genetic compatibility and risks posed by that person.

Some companies and other actors make extravagant, unsupported claims about how genetic testing can predict and prevent future disease. For example, a company called DNA Dynasty (now apparently out of business) marketed a “detailed DNA Disease Susceptibility test for over 100 diseases to identify precisely what your genetically inherited diseases are.” The company claimed that the results of their test would allow the customer to “lead a wonderful, active and lasting healthy life riding into the sunset, free from chronic degenerative diseases.” The website further claimed that “DNA Dynasty takes Health prevention to a whole new level. . . . To predict with 99% accuracy through Genetic Analysis the probability of a disease occurring in an individual through his/her genetic makeup.”

Another dubious medical application comes from spas and online sites offering gene-based treatments for skin and nutritional health. For example, in 2007 the MGM Grand in Las Vegas began offering genetic cheek swabs for dietary recommendations based on variations in six genes linked to nutrient metabolism. Other high-end spas offer diverse genetic tests for nutrigenomic strategies, fitness-focused tests that allegedly identify a client's optimal

training protocol, and testing of telomeres to determine a client's “true” cellular age.

Overly exuberant claims about the power of genetics have been applied in toxic tort cases to evaluate medical causation. A few years ago the Cytokine Institute claimed to have developed a proprietary genetic microarray test (msds1™ test) that “relies on no less than 22,000 DNA-based parameters” to determine whether benzene caused a worker's cancer. The test was apparently used in several worker's compensation cases. Geneticist Martyn Smith wrote a devastating attack on the test, arguing that “There is no possibility that it can reliably help us assign causation in relation to benzene exposure” and “is clearly junk science.” He continued that “the msds1™ test has never been subject to an analysis of sensitivity, specificity or positive predictive value” and that “[n]o knowledgeable scientist would accept the msds1™ test as useful information in attributing disease causation.” In a related context, the Burlington Northern Santa Fe Railroad was sued after it secretly tested the genes of employees who had brought worker compensation claims, apparently in the hope of finding a very rare gene variant that was associated with carpal tunnel syndrome.

In addition to dubious health claims for genetic data, a related problem is erroneous application of valid genetic health data. Studies have documented a high rate of misapplication and misunderstanding of genetic information by health care providers, most of whom did not receive significant education about genetics in their professional training. For example, a study published in 2011 by ARUP Laboratories found that clinicians ordered the wrong genetic test approximately 30 percent of the time over a 10-month period. A previous study of individuals who had been genetically tested for their risk of colon cancer found that physicians misinterpreted the test results in 31.6 percent of the cases. Although these errors in applying valid genetic data may be more innocent than the deliberate misuse of genetic data discussed

above, the impact on the patient is the same: they receive invalid data.

Problematic Products

A number of products that incorporate genetic testing involve pseudoscience. For example, a number of companies sold expensive nutraceuticals supposedly tailored to the customer's own genotype. Some of these products claimed to tailor the supplement based on testing of the customer's DNA. Others simply claimed the use of DNA or genetics without any actual data. For example, one company sold "BioEnhance with DNable" that claimed to be the first "multivitamin formulation that is also a genetic formulation," without any information on how genetics helped formulate the product. Nor did the vendor acquire any DNA from the customer. In 2006 the US Government Accountability Office (GAO) found that the sellers of these products were misleading consumers. The products, priced from \$1,200 to \$1,800 per year, differed little from commonly available multivitamins. Though the companies criticized in that GAO report no longer market products, new businesses have arisen that make equally dubious claims. For example, one website (www.customizednutrients.com) sells "geneME" Genetically Customized Supplements" that claim to provide "a revolutionary, personalized, 'just-for-you' nutritional supplement that is customized to your unique genetic code." A red flag for many such products is that they identify neither which genes they test for nor the scientific studies on which they base their conclusions. All they say is that they use a "12 key gene personalized DNA formula."

Other examples of genetics-based products with questionable scientific legitimacy are websites that provide genetic testing to allegedly determine romantic compatibility. For example, GenePartner.com's website claims that its "biological matching method is designed as a complementary service for matchmakers and online dating sites. Based on the genetic profile of the client, the GenePartner formula determines the

level of genetic compatibility with the person they are interested in. The probability for successful and long-lasting romantic relationships is greatest in couples with high genetic compatibility." Although the website refers to some scientific studies that show a correlation between genetic traits and romantic compatibility, this service appears to go beyond the limits of the available science. Yet another company (www.mydnafragrance.com) offers perfumes specific to individual human genetic codes.

Genetically modified (GM) foods are the subjects of some of the most sensational and egregious distortions of any genetic application, including the term "Frankenfoods" frequently used in the media. Every reputable scientific body, including the National Academy of Sciences, American Association for the Advancement of Science (AAAS), and the European Union's own scientific advisers that has examined the issue has concluded that GM foods are as safe or safer than conventional foods. Yet media attention on this technology has been swayed by bogus claims, ranging from Jeremy Rifkin's assertion in the 1990s that innocuous "ice-minus" bacteria must bring global cataclysm by destroying the entire atmosphere, to more recent false alarms by the likes of Jeffrey Smith. He is often portrayed in the media as an expert on biotechnology. Yet prominent scientist Bruce Chassy describes him as someone whose "only professional experience prior to taking up his crusade against biotechnology is [as] a ballroom-dance teacher, yogic flying instructor, and political candidate for the Maharishi cult's natural law party."

Conclusion

The examples provided here of hype, scams, exaggerated claims, and charlatans exploiting the public interest in genetics are a small sampling of the numerous misuses of genetic information in the media, legal, consumer, and medical realms. As genetics comes to play an increasingly important, legitimate role in all these spheres, it will become critical to police the claims made and to expose those genetic claims, products, and services that lack validity. ♦

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