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ORIGINAL ARTICLE

Captious certainties: makings, meanings and misreadings of consumer-oriented genetic testing

Norbert W. Paul · Mita Banerjee · Susanne Michl

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Abstract Members of the scientific and medical communities concerned with genetic testing might wonder, why cultural and ethical analyses of genetic testing are increasing again, especially since legal frameworks have, by now, come to provide more solid grounds for the routine application of genetic testing on both levels of application, diagnostics, and prediction. This contribution aims to shed light on the changing concept of genetic testing as it is raised by novel cultural practices and perceptions mainly triggered by direct-to-consumer predictive testing, including the phenomenon of a new genetic exceptionalism "from below". We are seeking to determine what is at stake in this practice and what consequences arise from it for the medical and scientific community. What exactly happens as we move from diagnostic to prognostic medicine? Above all, this article pivots on the notion of captious certainties, a concept, which we will elaborate on as our argument progresses.

Keywords Direct-to-consumer testing · Genetic predisposition of disease · Genetic exceptionalism · Medical ethics · Predictive genetic testing · Primary prevention

Background

Medical genomics in general and genetic testing, in particular, are certainly among those particular biomedical practices which have been exhaustively analyzed by international endeavors in bioethics (Sloan 2000; Kollek and Lemke 2008). In addition to these academic approaches towards the normative implications of genetic testing, the legislation of some countries—such as the recent "Genetic Diagnosis Act" (Gendiagnostikgesetz 2009)—may have put an end to any uncertainty regarding the ways in which we treat genetic information. Nevertheless, we are currently witnessing an interesting societal shift regarding the notions of genetic knowledge: The search for genetic information has become a routine procedure in the process of differential diagnosis and therapy planning (e.g., in oncology or metabolic disorders with a genomic component) and is thus treated like any other biomarker. *Predictive* genetic testing which was once considered a rather unusual and exceptional way of knowing one's health risks and of acting accordingly has, by now, entered the public arena under the premises of a growing health market and the ideal of empowering people to take charge of their own (future) health. As a consequence, genetic testing has lost its uniqueness and has become a marketable commodity. This shift—the social recognition of a predictive option offered by modern biomedicine, which in its turn triggers an (economic) demand for these services—concerns us in this paper.

Even though a predictive molecular medicine leading to effective causal strategies of prevention is far from being reality, genetic testing has crossed the line from the classical medical realm of the doctor–patient encounter to the health market on which it is being sold just like any other product available for lifestyle choices (Gollustet al. 2002; Lemke and Kollek 2011; Hogarth 2010). The emergence of Biotech companies, such as deCODEme or 23andme, the majority of which are based in the USA, best illustrates the fact that health-related knowledge has become a commodity driven by the market forces of supply and demand. Although many companies sell their products without a physician or a geneticist as intermediaries, some of them have successfully applied for FDA approval and turned to a model, which includes a health care professional (Howard and Borry 2012). It remains

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N. W. Paul (✉) · S. Michl
University Medical Center of the Johannes Gutenberg University Mainz, Mainz, Germany
e-mail: npaul@uni-mainz.de

M. Banerjee
Johannes Gutenberg University Mainz, Mainz, Germany

to be seen how far this modulates the current effects of direct-to-consumer marketing of genetic testing or if there is an economic pull for physicians to participate in and contribute to this market.

Yet, social demand cannot easily be distinguished from the logic of the market. Rather, the market suppliers of genetic testing may not only respond to, but may *create* a need for services of genetic testing. While the interface between the development of modern medicine and the economic marketing of these medical innovations has often been addressed by medical sociologists and medical historians (Wohl 1984; Starr 1984), it seems to resurface with a particular power when genetic testing is concerned. The slogan that "we are our genes", that our genes determine how our life will turn out, has not only become a cultural icon (Nelkin and Lindee1995), but keeps being reiterated in ever-new constellations and possibilities. What this logic obfuscates is how this information—the future described by or inscribed in our genes—is then to be used. Once we know that we are at risk for developing a certain disease, how do we deal with this knowledge? Thus, we suggest in this article that reducing the problem of "genetic risk" to the outcomes of genetic testing alone may miss the point.

Moreover, what may be at stake on an epistemological level is the value we accord to biomedicine as a discipline in general. To the extent that biomedicine has emerged as one of the leading disciplines (*Leitdisziplinen*) of the new millennium, the power it is said to have is nothing less than the ability to control the biological contingencies of human life and of prophesying our biological future. The problem, then, may arise not only from what biomedicine actually is capable of doing or its performability, but also from what social and cultural expectations are projected on the surface of biomedical innovation. For all the complexities of biomedicine as a field of knowledge, reducing those constellations of intertwined issues at the interfaces of biomedical knowledge, clinical practices, and their socio-cultural perceptions and their use to biomedical solutions alone may thus be short-sighted. This is especially true in a situation, in which concepts of disease are becoming increasingly predictive and medical interventions are more and more preventive, from the preventive drug regimens of our daily lives to the preventive intervention in the operating theater.

All in all, this paper addresses the often-neglected need to differentiate the diverse levels of applications of genetic testing on one hand, and the respective perceptions in the biomedical, the economical, and the socio-cultural spheres on the other. The main goal of our analysis is to explicate the normative underpinnings of non-medical and non-professional readings and misreadings of genetic information for biomedicine and to identify the levels on which these readings and misreadings require a more reflexive approach towards the socio-cultural context. We will explore the levels on which a more active involvement of the scientific and biomedical communities in the public discourse is strongly needed.

What is at stake?

As mentioned above, we have observed a subtle shift of medicine from a diagnostic towards a more prognostic–preventive approach during the last three decades. Health, as a key concept of medicine, is increasingly conceived as *future* health. For many individuals, it is a daily experience that they take medications in order to control serum levels of cholesterol, to substitute hormones, even to modulate cognitive abilities in order to prevent disease such as cardiovascular disease, osteoporosis, or Alzheimer's disease. Not surprisingly, diagnosis is increasingly complemented by prognosis. Epistemologically, diagnosis is related to calculable probabilities, whereas prognosis refers to non-calculable chance and uncertainty supported by judgments based on real world-experience. Genetic testing offers both: diagnostic and prognostic knowledge.

Even though prognosis like diagnosis falls within the realm of medical competencies, physicians are more dependent on diagnostic knowledge in order to determine the next step of diagnosis and/or intervention. By contrast, patients are usually more interested in the question of certainty and prediction: "How severe is my disease? How long will it last? Will I recover?" They are thus interested on the impact on which the diagnosis will have on their life world. It is at this juncture that the power of biomedicine and the prediction of genetic risk emerge. For as the possibilities of what biomedicine can do expand, it has become all the more difficult for us to cope with uncertainty and with the contingency of future life. From the perspective of medical ethics, the dichotomy between certainty and uncertainty, between causality and contingency is hence at the core of the recent debate on genetic risk. It is for this reason that we have chosen the concept of "captious certainty" to highlight the fact that these dichotomies are in fact not as clear cut as they may seem. Rather, genetic testing may offer a semblance of certainty, as the seeming possibility of containing contingency and clearly defining or predicting the future. Yet, as certainties, they are both captious and capricious: they may say more about our need of controlling contingencies than they may offer applicable solution, once and for all, to the tangible problem—and the reality—of contingency in our everyday lives.

At the same time, because genetic testing has become a medical necessity for some aspects of diagnosis and treatment as much as it is now an industry offering services directly to consumers, it has profound effects on reconfiguring the doctor–patient relationship. Not surprisingly, the commercial companies offering prognostic, health-related knowledge directly address consumer needs. Even when these services

include a health care professional, he appears to be a "technical" expert providing the service sold by the company rather than a physician taking care of his patient. In any case, the role of the physician seems to be limited in this context. Apparently, there is a large demand for self-administered predictive tests. Yet, this demand, too, may be in flux. In a systematic review of the literature on user perspectives, Goldsmith et al. (2013) state that there may be an increasing preference for accessing genetic testing via health care professionals and for discussing the results with them (see also Howard and Borry2013). However, we know little of consumer attitudes and of consumers' motivations for undertaking such testing; as yet, the results of these mostly non-representatives studies are not robust enough to draw any conclusions, especially since consumer behavior might vary substantially depending on social and cultural contexts, ranging from pure curiosity to anxieties and worries about one's own future health or the health of one's close relatives (Howard and Borry 2011; Vayena et al. 2012; Blosset al. 2013; Goldsmith et al. 2013)

In the case of predictive genetic testing, the prognosis not only refers to the patient or person himself but is bound up in a family history, as the information provided by genetic testing may also refer to the patient's ancestry, children, and even his grandchildren. Thus, genetic testing, potentially, has the power to predict not only a single life and the future of a single person, but it may come to predict the outline of the biological future of generations to come. In this sense, then, having oneself genetically tested may be more than an individual choice. It may entail not only one's own decision to know one's genetic future, but may involve depriving others —one's children or grandchildren—of the right *not* to know.

As the right to know or, perhaps even more significantly for an ethical discussion of genetic testing, the right not to know, genetic testing is itself bound up with legal frameworks. Here, globalized biomedical knowledge and the services offered on a global market are translated into local, situated practices regulated by ethical frameworks and legal regulation, which are nationally specific (Borry et al. 2012). When we take the German situation mainly shaped by the German Genetic Diagnostics Act as a case in point, it becomes evident that the scope of genetic testing is bound to particular parameters and involves mandatory genetic counseling (Duttge et al.2011). Yet, it is not quite clear how the latter mandate is to be understood. It has been discussed, whether genetic counseling should be done by geneticists with medical expertise or by physicians with genetic expertise. While the first view stresses the need for independent expertise, the second one focuses on the importance of an established patient–physician relation in setting the therapeutic or preventive goals according to the feasible, desirable, and justifiable options. Especially the dissemination of genetic testing amongst clinical specialties (Obstetrics and Gynecology, Pediatrics, Oncology, Dermatology, etc.) calls for an adjustment of the role of genetics and genetic counseling. Finally, the janus-faced nature of genetic information needs to be addressed: what, precisely, is involved as we move from diagnosis to prognosis?

A "historical" vignette

Let us illustrate these interrelated issues involving captious certainties as well as readings and misreadings of genetic information with a case study presented to the scientific community by Francis Collins in his Shattuck Lecture (Collins 1999).

Collins illustrates the potential future of genetic testing by referring to a hypothetical person, John, who gets a medical check-up when applying for a new job. He is diagnosed with having a significantly elevated level of cholesterol; there is a known family history of cardiovascular disease (John's father died from cardiac infarction at age 49). As a consequence, the physician offers a number of genetic tests to John in order to check for genetic health risks. The patient is a heavy smoker, he does not exercise regularly, and is overweight. John decides to have those traits genetically tested, for which preventive strategies do exist. The idea involved in this practice of genetic testing is to empower John in a way that he can better take charge of his specific health risks.

It is here that the dilemma between captious certainties and manifest confusions presents itself. Thus, John's potential reaction holds some captious certainties: First and foremost, behavioral and lifestyle-related health risk are addressed and genetic information at first leads the physician to emphasize the need for a life-long change of health-related behavior and the reduction of individual lifestyle risks: John may quit smoking and start exercising more regularly to lose weight. Furthermore, the actualization of genetic risk needs to be monitored more closely than in other patients and because of an elevated life-time risk John may have to undergo regular annual coloscopies. Collins (1999) also envisages the shift to more individualized options for preventive strategies tailored to John's specific genotype and for drugs (e.g., for the control of lipids) adjusted to John's particular genetic and metabolic make-up as a step towards pharmacogenetics and pharmacogenomics. However, in this paper, we will focus on the aspect of predictive testing and direct-to-consumer marketing, not least because the aspects of a genomic-based individualization of medicine have been discussed in greater detail in other papers (Paul and Roses 2003; Paul 2004; Paul 2010; Kollek 2012).

While this vignette rightly addresses the options for controlling internal, person-related risk by behavioral prevention as well as via the public responsibility to provide viable options for the control of environmental risk, genetic risk needs to be understood much more as an embodied risk for which no accepted strategies of prevention exist; other than that, we may be willing to accept notions of a genotype-related

prevention aiming at avoidance of undesired genotypes (e.g., by pre-implantation diagnostics or abortion) and the interruption of disadvantageous interactions of individual genomes and a potentially pathogenic environment (e.g., by genome-based employment strategies). It is for this reason, that the certainty, which John has been offered may prove to be captious, as the relationship of behavioral change to genetic risk factors cannot establish any causal link between genetic risk and its control. Can our way of life change our genes? The answer to this question is far from certain and as multifold as the levels on which it is perceived, discussed, and reinterpreted.

Making, meanings, and misreadings

By and large, genetic information is still regarded to be exceptional in many ways. However, a clear distinction between diagnostic and predictive genetic testing and a closer look at its very function in the realm of differential medical diagnosis provides a different image. So, let us have a brief look at clinical biomarkers compared to genetic information (Table 1).

It is obvious that the results of genetic testing are not fundamentally different from results of many other biomarker tests. Rather, what may differ is the value and power ascribed to genetic testing. The difference lies, in part, in a shifting perspective from diagnostic to prognostic uses of genetic information. In the realm of differential diagnostics addressing actual findings and pathological or physiological processes (such as differences in drug metabolism), genome-based tests do not significantly differ from other molecular markers. They are not "exceptional." In the realm of individual health prognostics, however, genetic knowledge is dealt with in a way that may very well lead to a new "genetic exceptionalism from below" (Paul and Ilkilic 2009). It is the incessant cultural reinforcement of the mantra of empowerment which has already led to a situation, in which every bit and piece of information that may help us control the contingencies of our lives and which thus lead to a (competitive) advantage in the struggle for social and economic resources which emerges here. Furthermore, this "pull" of the market is fueled by scarcity in most health care systems, which in turn, leads to a shift from public responsibility (public health) to the privatization of health responsibilities (health markets). In this arena, genetic information is increasingly regarded an exceptional asset to understand, plan, and control one's biological future and to take responsibility for individual health risk (Paul 2005). The value-ladden debate on the preventive mastectomy of the US American actress Angelina Jolie is a recent and vivid example of the popularization of genetic responsibility.

One of the sources of misreadings of predictive genetic information is a confusion of probabilistic measures of risk (Tartter et al. 2002) addressing the frequencies of the association of a certain genotype with a certain phenotype with the actual personal or individual risk (Gail and Greene 2000; MacKarem et al. 2001; Euhuset al. 2002). The public may demand services of genetic testing, then, even if the information thus obtained is far from self-evident from a scientific perspective.

This is not a new finding, however. The example of breast cancer susceptibility testing as performed in the US at the end of the 1990s, the commercially available tests for BRCA1/2, which are now the most widespread predictive tests for a late onset of disease historically led to a new notion of embodied risk and the so-called "healthy ill" (Feuer et al. 1993; Lermann et al. 1998; Kuschel et al. 2000). Genetic "impairment" could not be addressed by established strategies of risk control

Table 1 Comparison of clinical biomarkers with genome-based markers

	Clinical biomarkers	Genome-based markers
Origin of samples	In patients (in vivo) From specimen and biomaterials apart from patients (in vitro) From conserved ("dead") materials (in vitro)	In patients (in vivo) From specimen and biomaterials apart from patients (in vitro) From conserved ("dead") materials (in vitro)
Levels of analysis	Physiological traits Morphological traits and function (x-ray, angiography, mammography, CT, MRI) Molecular markers (antigens, tumor-markers, proteins, hormones, etc.) Cell-based markers (free tumor cells, cell counts, cell morphology, etc.)	Chromosomal characteristics and aberrations (karyotype) Specific mutations of genes or nucleotides (NAT-2, BRCA, APOE/SNPS, etc.) Genetic variability of functional genes/alleles (CYP-450, etc.) Epigenetic factors (change in gene activity without alteration of the gene sequence)
Pre-conditions for clinical use	Sensitivity and specificity must be balanced and validated Tests must be safe, robust and reliable Tests should be as minimally invasive as possible Tests can be routinely performed due to practicability and affordability	Valid statistical correlation of genetic information with clinical phenotypes (in general) Robust clinical interrelation of genetic information and individual phenotype (case by case) Time efficiency and cost efficiency in relation to clinical efficacy

(behavior, environment) and thus led to a more radical response of the surgical removal of the breast (Meijers-Heijboer et al. 2000; Eisen and Weber 2001).

While the scientific and medical community has long since come to grips with the different levels of genetic evidence and the epistemological underpinnings of prediction, it seems to be the culturally ascribed obligation of individuals taking charge of their own genetic risk which triggers a public response to and demand for services of genetic testing in a rather uncritical way. Hence, it needs to be stressed that the dissemination of genetic services via the internet sheds new light on some rather old arguments.

Sometimes, the prediction of disease risk can be very easy. One could reasonably make the point that every man will develop cancerous cells in his prostate if only he is getting old enough. However, in almost every case of direct-to-consumer genetic services, genetic information is deliberately used to create a captious certainty that is simply wrong, unless you read the well-hidden fine print of the offer. Disease entities with a considerable genetic contribution are treated as being on a par with disease entities with only relatively scant impact of genes. The completeness of the genetic profile (together with the completeness of ordered profiling services) is, of course, closely related to the mantra and the market of empowerment. Genetic information is increasingly marketed as a means of empowering individuals to control their personal risk and to take charge of their biological future. This strategy fits well into the changing conceptions and ethical assessment, which have been prevalent since the second half of the twentieth century, i.e., the emphasis on of the principle of autonomy. Ideally, an increase in knowledge about individual, health-related traits is also an increase in the ethically and socially dominant principle of autonomy. As briefly mentioned above, the appreciation of autonomy is fueled by a shift from public to personal responsibility for health in most Western health care systems. In this context, risk-adjusted health-related behavior is reshaped into an obligation and thus leads to a loss of autonomy. Especially in health-care systems based on a shared responsibility between the individual and the community, predictive information reallocates attention towards an emphasis on individual responsibility despite the relative predictive power of genetic information and the restricted means of controlling health risks.

Conclusion

It might be bewildering, but in the end, one question which needs to be addressed is the logic of supply and demand. There is a market for genetic services, because they satisfy a cultural need. They satisfy the need for certainty, for the mastering of contingency in an age in which biomedicine seems to reign supreme and in which the contingencies of human life seem to be controllable by the life sciences and their allied technologies. This leads to a number of cultural misreadings, which need to be taken into account by both, the scientific and the medical communities in order to prevent a harmful projection of misreadings on experimental research in genomics as well as on genome-based biomedical practices. It needs to be communicated more clearly and proactively, that

- Most genetic risk factors related to epidemiologically relevant health risks accessible to prevention do not show a causal correlation between risk and the future state of health;
- The interplay between genes, behavior, and environment makes evident that all three levels need to be addressed;
- Genetic risk is embodied risk and the principle of justice demands that individual responsibility must focus on behavioral strategies *and* public responsibility on environmental strategies of prevention.

Controlling the contingencies of our biology by preventing disease and intervening in pathological processes has long since been one of the prime tasks of biomedicine. In this regard, genetic knowledge is seemingly vested to control and prevent inherited risk on the one hand and to better understand and manage the processes of the human body on the other hand. By its very nature, genetic knowledge is probabilistic and the human genome is rather a dynamic entity rather than a static code. So, while informed members of both the community of geneticists and the community of ethicists are well aware that the notion genetic exceptionalism is based on a long since obsolete genetic determinism, the public, now market-driven reading of genetic information is likely to induce a new genetic exceptionalism from below forcing us, from an ethical point of view, to engage in a public discourse that has now been silenced by the advent of other "hot topics" in the agora of public debates, such as advances in the neurosciences. While from the point of view of medical genomics, genetic determinism has long become obsolete, consumer-oriented genetic testing reintroduces a deterministic view of the gene. "Know your genes, know your risk, know yourself" is not only a marketing strategy based on a deterministic simplification of genetic information, but it has already generated a novel genetic exceptionalism from below. Especially when it comes to understanding and controlling genetic risk, this common misreading of genetic information creates captious certainties of not being at risk. Certainties become captious whenever the absence of genetic risk is confused with the absence of risk as such or if controlling genetic risk (e.g., by genomically targeted measures of prevention) is misunderstood as a more comprehensive control of health risk.

There is no doubt that genetic testing as a service-for-fee will continue, especially those services promoted by web-based providers. Consumer interest is triggered by an ever-increasing individual responsibility for health, amalgamated

with a discourse of self-determination and empowerment. In this market-driven context, genetic information is very likely to be dealt with as a commodity, as an asset for individual life-planning regardless of the relative prognostic power inherent in most genetic information. A medically useful, socially acceptable and ethically justifiable approach to genetic testing, on the other hand, will treat genetic information as non-exceptional findings in the process of biomarker-based differential diagnostics when appropriate (e.g., tumor-types). It will furthermore contextualize and explain the individual meaning of genetic information whenever prognostic information is generated or whenever a third party is affected by the information (right not to know) and will address the relative explanatory reach of genetic information in genetic counseling. This may also mean to unmask consumer-oriented genetic testing as a service for fee without adequate counseling whenever possible. All in all, we have to acknowledge that biomedicine, biotechnology, and the life sciences are cultural practices themselves and hence have a social and political impact demanding not only adequate communication about the explanatory reach of models, the reliability of tests and the safety of interventions, but also an appreciation of the reflexivity enabling us to deal with common readings and misreadings of what biomedicine can and cannot do.

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