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Title: Ethics, genetic testing, and athletic talent: children's best interests, and the right to an open (athletic) future

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ABSTRACT

In this paper we discuss the ethics of genetics-based talent identification programmes in sports. We discuss the validity and reliability of the tests and the claims made by direct to consumer companies, before presenting a range of ethical issues concerning child-parent/guardian relations raised by these tests, which we frame in terms of parental/guardian duties, children's rights, and best interests. We argue that greater ethical emphasis needs to be put on the parental decision on the wellbeing on the child going forward, not on *ex post* justifications on the basis of good and bad consequences. Best Interests decisions, made by a third party seem to comprise both subjective and objective elements but only a holistic approach can do justice to these questions by addressing the wellbeing of the child in a temporal manner and taking into account the child's perspective on its wellbeing. Such decisions must address wider questions of what a good (sports)parent ought do to help the child flourish and how to balance the future-adult focus necessary to nurture talent with the wellbeing of the child in the present. We conclude that current genetic tests for 'talent' do not predict aptitude or success to any significant degree and are therefore only marginally pertinent for talent identification. Claims that go beyond current science are culpable, and attempt to exploit widespread but naïve perceptions of the efficacy of genetics information to predict athletic futures. Sports physicians and health care professionals involved in sport medicine should therefore discourage the use of these tests.

Key-words:

children, talent, genetics, future, ethics, direct-to-consumer.

Word-count:

3246

1. INTRODUCTION

School playgrounds are the traditional sites of basic talent identification systems where team captains select, one by one, from the most to the least able and desirable teammates. Nowadays, it seems, we should instead ask our children for a cheek swab to genetically test their athletic potential. It is not clear that there are gains in efficacy despite advances in science and technology, since questions of reliability and validity remain. We critically discuss here the conceptual and ethical questions arising from the use of genetically-based approaches to athletic talent identification.

2. WHAT DO GENETIC TESTS FOR ATHLETIC TALENT IDENTIFY?

Genetic polymorphisms are defined as naturally occurring variations (usually at a single base pair of DNA, although they can involve longer stretches of DNA), which involve one of two or more variants of a particular DNA sequence (NCBI definition). If occurring at a single nucleotide polymorphism (as is the case for most Performance Enhancing Polymorphisms, or PEPs), they are called a single nucleotide polymorphism (SNP). Most of these variations are neutral (i.e. they do not change the encoded amino acid, or for which there is no established phenotype), but some correlate with susceptibility to disease, drug response, or with other phenotypes (e.g. the distribution of muscle fiber types). Recent years have witnessed the rise of a market in direct-to-consumer (DTC) tests to identify children's athletic talents with a focus of testing for SNPs. In the USA alone there are at least seven companies that currently sell DTC-genetic tests for sports performance or related traits targeting children.(28,33). There are companies also based in the UK such as "DNA Fit", which sells "genetic information for fitness and nutrition" (although the target here seems to be adults). Coaches, trainers and parents are the target populations. The tests are relatively cheap ranging from under \$100 to about \$1,000, depending on the number of SNPs being tested.

Beyond the commercial sector there are government-sponsored programmes to cultivate future Olympic Champions have taken a genetic turn: for example, China's nation-wide boarding schools for talent identification,(20) and Uzbekistan's national genetic screening programmes endorsed by National Olympic Committee.(30)

While most DTC companies are US-based their services are offered globally. As a predominantly an on-line international market, it is difficult to regulate. The UK Human Genetics Commission (dismantled in 2012) and the European Society of Human Genetics recommend that genetic tests be provided with appropriate genetic counseling.(23,21) In Europe, tests for talent are potentially in breach of Council of Europe Bioethics Convention article 12, which sets out a strict therapeutic or preventative rationale for genetic tests.(8) In the US, the American Academy of Pediatrics and the American College of Medical Genetics and Genomics published guidelines in 2013 on the genetic testing of minors strongly discouraging the use of DTC- testing because of "lack of oversight on test content, accuracy and interpretation". (27) Specifically in the context of sport, the NHMRC of Australia has released guidelines in November 2013 discouraging DNA testing for talent identification in sport.(24), and in November 2015 The British Journal of Sport Medicine also recently released a joint consensus statement clearly stating that "With regard to predicting future sporting performance, the scientific foundation is extremely limited and largely non-existent. There is concern among the scientific community that the current level of knowledge is being misrepresented implicitly for commercial purposes." (32: 1490)

Talent identification is seen an effective first step on the path to athletic success.. On the basis of the results of these tests parents and coaches may identify, plan and invest in the children's future. Perhaps surprisingly the central concept "talent" is far from clearly mapped or universally agreed upon.

In the literature on talent identification the most widely cited text is Baker and Cobley (3: p.3) who in their review of evaluation of the strengths and weaknesses of contemporary systems for identifying and developing talent in sport define talent as:

"the quality (or qualities) identified at an earlier time that promotes (or predicts) exceptionality at a future time."(3)

Consistent with the above they refer to “talent identification” (p. 5) as the

“process of recognising and selecting players, through a series of testing and subjective assessment procedures, who show potential to excel at a more advanced level of competition” (3)

There are at least two conceptual problems with these definitions. The first does not track common linguistic usage. Thus, for example, the Oxford English Dictionary, defines talent as a “natural aptitude or skill”. Secondly, Baker and co-authors link talent to *future* as opposed to present ability. In addition, there are two problematic assumptions that underpin empirical research and applied practices in sport talent identification (and its development) that are recognized by Baker and co-authors. The first one is that talent is identifiable and quantifiable. The second is that adult performance can be predicted by earlier performance through specific ‘markers’ such as speed tests, power tests, or genetic markers. In the case of genetic-based talent identification, the dominant assumption is that athletic excellence can be traced back to specific genetic polymorphisms.

3. ARE GENETICS-BASED TALENT IDENTIFICATION PROGRAMMES SCIENTIFICALLY SOUND?

Genetic variations or performance enhancing polymorphisms (PEP) have increasingly been identified in recent years (25, 9, 26). With costs of DNA sequencing dramatically decreasing, a growth trend is reasonably predictable. Despite the increasing complexity and sophistication of genetic science in sport,, the assumption that athletic excellence can be traced back to specific genetic polymorphisms is a remarkably simplistic assumption. Most of these tests are based of genome wide association studies (GWAS) that merely detect statistical links between variants of a particular genetic polymorphism and a phenotype. They cannot prove that the gene variant is casually related to, e.g a disease, nor does they tell researchers anything about the function of the gene and how it may be involved in the condition: a statistical association does not entail an association of any clinical utility.(18) In addition, in the case of genetic testing for talent, there is a further problem of

transferability. PEPs are identified on elite athletes and their significance is then extrapolated to a completely different population, i.e. children often of a different ethnic background.(11)

The test for the alfa-actinin 3 polymorphism (ACTN3) exemplifies many of the problems inherent in these genetics-based talent-identification tests. The ACTN3 gene codes for the actin-binding protein alfa-actinin, where actin is an integral component of the protein super-structure that generates contractile force within muscle fibers. Polymorphisms in ACTN3 are thought to contribute to the heritability of fiber-type distribution in muscle, where the Type I are slow-twitch fibres that metabolise aerobically and are used in endurance races, while Type II are fast-twitch fibres that metabolise anaerobically, and are used in sprints.(25,34) The test for ‘ACTN3 Sports Gene’ is marketed as a genetic ‘Power/Speed performance test’, with the aim to give ‘parents and coaches early information on their child’s genetic predisposition for success in team or individual speed/power or endurance sports’.(2)

Genetic scientists give no support to this bold assertion. While tests for ACTN3 variants claim to assess the predisposition to athletic ability and prowess, the ACTN3 gene accounts for only 2% of total variance in muscle performance.(9) The rest of the variation is determined by a wide range of genetic and environmental factors, only a fraction of which are understood.(9) Moreover, the fact that there is a higher frequency of ACTN3 polymorphism in elite sprinters does not allow prediction of athletic performance, as muscle performance is merely one component of athletic performance.(19) Moreover, as the systematic review and meta-analysis by Ma and co-authors demonstrates (18), only two statistically significant associations have been demonstrated between the angiotensin I converting enzyme and endurance events, and the ACTN3 association with power performance. Notwithstanding these, other polymorphisms offered by the DTC companies fail to reach statistical association, let alone clinical utility or predictive power. In addition, what we know so far on the genetic basis of sport performance has been generated using relatively small cohorts of less than 300 individuals.(9)

In his classification of DTC-genetic tests, Caulfield (2011) establishes a continuum between “marginally pertinent”, “vaguely predictive”, and “clearly preposterous”.(6) At best DTC-genetic tests for talent identification may be classified as ‘marginally pertinent’ because despite advances in the genetic basis of sports performance, their

capability to predict future performance is very weak, if not non-existent (32). DTC companies grossly distort the power of these tests and their utility in athletic career planning – both in terms of de/selecting sports that an individual is apparently genetically suited to or not.

4. ETHICS OF GENETICS-BASED TALENT IDENTIFICATION PROGRAMMES: PARENTAL DUTIES, CHILDREN’S RIGHTS, BEST INTERESTS

Athletic genetic tests are predicated on the assumption that an early intervention and steering from parents in a scientifically-guided direction can lead to future success. Is there anything morally different between more traditional programmes of talent identification and genetics-based programs? One key difference attends to perceptions as to their efficacy. Genetics-based talent identification (TI) programmes are often thought of as particularly powerful because of the exceptional “deterministic” status still accorded to genetic information by the public.(11)

Breitbart et al in their review of genetics-based talent identification programmes (4:1493) argue that “the procedure of a TI-based selection remains ethically questionable because the applied tests and the unreliable extrapolation of future success exhibit false positive and false negatives” which is consistent with the position developed here. Yet they conclude that “many deficiencies in the current TI system and research have gained attention, and efforts are being made to overcome them”.(4) This is a laudable yet flawed conclusion since it conflates scientific or technical deficiencies with conceptual ones. While there are technical deficiencies that better designed methodologies will improve upon, there is a fundamental failure to acknowledge the limited value of TI predictions faced with the contingency of factors that comprise athletic success, and the contingencies of a human life over the long haul from childhood to adulthood. Moreover, discussion of talent identification often neglects deeper conceptual and ethical issues about child-parent/guardian (hereafter “parents”) relations, which can be framed variously in terms of ethical concepts such as duties, rights, interests.

Moral and legal rights are thought typically to be negative or positive; protective or promotive of the wellbeing of an individual. It is widely held that rights generate duties in relevant others to do or forbear specific things. According to the United Nations Convention on the Rights of the Child (31), children are accorded a wide range of specific rights. Article 3.1 notes “In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.”(31) How these concepts are framed against parental rights and duties is a key issue for talent identification programmes since, children do not typically not enjoy equal status in decision-making. This disparity is justified on the grounds that they do not possess the relevant degree of rational autonomy or, in legal terms, “competence”.

Moreover, given the disparity of knowledge and power between parents and children, there must be critical discussions about parental rights and duties, and about what it means to be a good (sports)parent (12). These discussions must be temporally framed: they necessarily involve evaluating what it is ethically justifiable now with an eye towards the consequences of these actions for the future, the opportunities they open up, and those which are foreclosed by decisions and actions taken in the present.

In an important contribution to the philosophical literature on children’s rights Feinberg originally coined the term “right to an open future” (ROF).(10) as a subset of child-related rights that were distinct from adult rights. Rather than expressing a general adult right to determine one’s choices and projects, the child’s rights he argued related to the adult that they would become. It was thus called a “right in trust” where parents act as fiduciaries for their child(ren). Feinberg’s discussion arose from a US Supreme Court decision that permitted the Amish community to end their children’s public schooling at age 14 years of age, before the end of compulsory schooling at 16. Children, he argued to the contrary, should be allowed to choose their own conception of the good later in life when they are able to exercise their autonomy, and parents have a duty not to force upon them life choices that would prevent them from exercising that autonomy at a later date.

What has this got to do with genetics-based talent identification programmes? It has been suggested that DTC genetic tests infringe on the child's ROF by limiting the opportunities that would be open to child to only one sporting future.(22) But this objection is only a part of the ethical evaluation of ROF and genetic testing. Consider a real-life example, the case of Andre Agassi. Both he and his older siblings were subjected to a highly focused and controlling education by their father.(1) Agassi became a world-renowned tennis player. Insofar as Agassi was brought up in the Bollettieri academy, where curricular options were especially narrow, and youngsters subjected to a highly controlled environment, should we conclude that his ROF were overridden? Our present perspective might justify in consequential terms the infringement of his ROF but this would not extend this to his elder siblings who failed to become successful tennis players.

The idea of an ROF is not without criticisms. Might parental child-rearing aimed at a "smorgasbord" of activities not also be detrimental to the promise of a child's particular talents?(17,5) Does ROF count against all forms of early specialization, which are necessarily exclusionary because of opportunity costs? The idea of a neutral, non-committal, openness to the future also fails to capture the palpable fact that some options are not equally valuable, nor necessarily combinable; nor realizable at the same life stage, but that they are still capable of rational evaluation.(12) It also fails to capture the widely held view that child-rearing children practices cannot avoid significant recognition of parental values.

ROF, like Best Interests decisions, made by a third party seem to comprise both subjective and objective elements.(16) Note, however, that if all choices are merely capable of subjective evaluation then, logically speaking, none are superior or inferior; they are merely matters of taste. Yet if the possibility of objective evaluation as to which choices may be preferable exists (e.g. more time spent on maths tuition, video game playing, paid employment, voluntary work, athletics, or piano lessons), then complex choices about uncertain and unpredictable futures can be justified by more than mere preferences. But neither ROF nor BI models provide us with a decision-procedure for specific guidance.

Just like adults, the child's development towards the good life is essentially both temporal, and social. Wellbeing is built within webs of relationships and contexts in which sense or meaning can be experienced. The way in which parental preferences become acquiesced to, endorsed, or rejected by maturing children and adolescents points both to the need to understand decisions re ROF or BI in a wider nexus of interests and desires. It seems that ROF is a static concept that does not adequately encapsulate the long-term, future selves, dimension of wellbeing.(29)

To a certain extent, decisions affecting the wellbeing of children and adults pans out in *media res*. That is to say, in the thick of things. We plan forward, guesstimating all manner of variables. Ethical evaluations must be made both *ex ante* (according to our responsible choices and predictions) and *ex post*. As put by Kierkegaard, life can only be understood backwards, but it must be lived forward.(15) It is this living forward, and the wellbeing of the child as she develops into an adult that must be foregrounded when considering the use of non-therapeutic genetic testing.

We argue that the ethical emphasis needs to be put on the parental decision *in light of the present tense*, on the wellbeing on the child now, not on (potential) *ex post* justifications in hindsight on the basis of the consequences. Only a holistic approach can do justice to these questions by addressing the wellbeing of the child in a temporal manner and would address wider questions of what a good (sports)parent ought do to help the child flourish, and how it would balance the future-agent focus necessary to nurture talent with the wellbeing of the child in the present.

5. Discussion: genetic tests and athletic futures?

The ethical issues with genetic based TI are not limited to the unreliable extrapolation of future success. Even counterfactually granting predictive value to genetic tests for talent identification does not rule out the ethical issues we have raised. Genetic tests for talent identification purposes rests upon substantial assumptions about the envisaged future. This limitation is intrinsic to prediction and not something that can be eradicated since what one is predicting is, in part, the shape of a human life. What we do now affects the future for good or worse: choices alter futures. And this is

amplified in the case of children and adolescents in the first phases of such a life. None of this amounts to the conclusion that we should not use genetic tests, nor that we should. How we approach the initial question responsibly depends on our understanding of the terms of reference, the reliability and validity of the tests, and, crucially, a range of ethical considerations about choice, consent, and responsibility for the future wellbeing of those whose life plans or prospectuses are neither fully formed nor informed.

DTC-genetic tests to identify talent in sport do not predict future sports performance while can “discourage parents and children from pursuing a particular sport interest if the genetic test does not confirm specific talents”, raising the very real possibility that parents and children may make “ life-decisions based on mistaken beliefs about the relevance of the tests”. (7) This supports the recent guidelines by British Journal of sports Medicine to discourage the use of such tests. (32)

Critically, public discussion needs to be opened on the meaning and value of sport and of physical activity in childhood and adolescence as compared to the meaning of sport in adult and especially professional athletics,(7) which is another source of pressures towards early specialization, and the role that sports medicine and technology ought to play mediating such information. Childhood and adolescent sport should not become so ‘goal-directed’ an activity that it aims exclusively at victory, or the early professionalization of children, as elite sport currently is. Most of the values and benefits of sports may be had by the modestly competent as well as the elite. Ruling out possible sources of meaning and wellbeing on the grounds of genetic ineptitude early in the life of a child is scientifically irresponsible, and ethically culpable.

Both ROF and BI judgments work against choosing a narrowly athletic path for any child that is not exceptionally athletically talented, the identification of which (i) only reveals itself after some years of play and sports experience; and (ii) is not reducible to genetic tests. Current genetic tests for ‘talent’ do not predict aptitude or success to any significant degree and are therefore only marginally pertinent and potentially very misleading for talent identification.(7) Sports physicians and health care professionals

involved in sport medicine should therefore not promote such tests, and should discourage parents or others who have accessed DTC tests to act on the basis of the results of the tests. Moreover, state-sponsored programmes such as those mentioned at the beginning of this paper should also be the subject of critical scientific and ethical scrutiny.

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No competing interests.

Contributorship statement

Both authors contributed equally to the manuscript.

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