Why Test Children for Adult-Onset Genetic Diseases?

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Abstract

The genetics community has developed guidelines recommending that predictive testing of children for adult-onset genetic conditions should be withheld. Genetics policy makers have maintained that their restriction of predictive testing of children is justified because (a) it shows respect for children's autonomy and confidentiality, (b) it protects children from harm, and (c) there are no compensating benefits of testing when no effective treatment for the condition is available. Although this approach seems reasonable on its face, a careful examination of the arguments shows that each of the three justifications for restricting testing is flawed. Specifically, I argue that the consensus position is not justified because (a) the appeal to autonomy in this context is baseless and confused, (b) there is no evidence of harm from disclosure, and (c) the claim that there are no benefits from early testing is based on an unjustifiably narrow view of benefits that ignores significant advantages that testing actually provides. Ultimately, for reasons that pediatricians usually consider important, I argue that pediatricians should encourage parents to pursue genetic testing of children at a young age.
Key Words: Genetic testing, predictive testing, adult-onset genetic diseases, genetic diseases.

PERHAPS AS A RESPONSE to the history of eugenics and perhaps as an attempt to distance modern genetics from that history, the community of genetics researchers, clinical geneticists, and genetics counselors has been remarkably proactive in considering the ethical implications of human genetics. They have identified principles for guiding their practice and developed policies, points to consider, and guidelines for helping practitioners to navigate their rapidly developing ethically hazardous clinical domain. As background to their efforts, the genetics community has implicitly endorsed three underlying precepts: (a) genetic information can be a significant medical and psychological benefit to patients/clients, (b) genetic information can help patients/clients to avoid significant harms, and (c) respect for autonomy is of special ethical importance. Based on these presumptions, the genetics community has developed a number of more specific and explicit principles for guiding their clinical practice:

- Tolerance of other reasonable points of view.
- Non-judgmental regard.
- Non-directive counseling.
- Informed consent.
- Confidentiality.

These principles echo the ethical commitments that Western medicine has embraced, and they reflect the current consensus of medical ethics.

Predictive Testing of Children for Adult-Onset Genetic Conditions

As part of their ongoing effort to assure that their practice is ethical, the genetics community has developed guidelines that are specifically relevant to predictive testing of children for adult-onset genetic conditions. In what follows, I shall discuss the recommendations that have been advanced for withholding testing, to determine whether these policies actually conform to their foundational principles. The testing policies that I am particularly concerned with in this discussion relate to genetic conditions for which there is no

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phenotypic evidence for disease at the time of testing (i.e., no signs or symptoms of disease). I shall not be discussing tests that yield ambiguous results, but rather those tests the results of which may indicate a high chance of developing the condition in the future. And I will only consider tests for conditions for which, currently, there is no treatment available to prevent or forestall the development of the condition. In other words, I shall be discussing policies relevant to predictive testing for serious familial conditions in which the family history makes it clear that the child has a very significant chance of developing the disease. I have in mind the testing of asymptomatic children for conditions such as:

- **Huntington's disease (HD)** (an inherited degenerative brain disorder associated with symptom onset and death in early adulthood). When one parent has the disease, a child has a 50% chance of inheriting the affected gene and developing the condition.
- **Polycystic kidney disease** (an inherited kidney disorder associated with kidney failure). When one parent has the disease, a child has a 50% chance of inheriting the affected gene and developing the condition.
- **Familial adenomatous polyposis coli** (an inherited disorder of the bowel associated with a very high incidence of early onset bowel cancer). When one parent has the disease, a child has a 50% chance of inheriting the affected gene and developing the condition.
- **Early-onset Alzheimer's disease** (an inherited degenerative brain disorder associated with symptom onset and death in early adulthood). When one parent has the disease, a child has an approximately 50% chance of inheriting the affected gene and developing the condition.
- **Early-onset breast or ovarian cancer** (an inherited disposition to develop breast or ovarian cancer in early adulthood). When one parent has the disease, a child has approximately a 25–30% chance of developing the condition.
- **Dominant variant of Charcot-Marie-Tooth disease** (an inherited degenerative nerve disorder). When one parent has the disease, a child has approximately a 50% chance of inheriting the affected gene and developing the condition.

Members of the genetics community have expressed their aversion to predictive testing of children for such adult-onset genetic diseases, and in the early 1990s they issued position statements that strongly advised against predictive testing of children for genetic diseases that begin in adulthood (1–3). These position statements do, however, acknowledge that there might be a very few "clear-cut and exceptional circumstances" that could justify testing in a particular case.

Genetics policy makers have offered three reasons to justify their restriction of predictive testing of children for adult onset genetic conditions. (a) They maintain that restricting predictive testing of children for adult-onset genetic conditions is respectful of autonomy and confidentiality because the decision is left to the patient, who will be able to decide when he or she becomes autonomous years down the road. By refusing to perform the test when an immature child and/or the parents request testing of the minor, the geneticist is preserving the decision for the future mature patient. Because the child is not tested now, the grown patient will be able to make the decision about whether or not to be tested and who should have access to the test results (4–6). (b) Geneticists also argue that the tests are harmful in that they carry a significant risk of the "unbearable certainty of knowing," damage to self-esteem, survivor guilt, and injury to the family dynamics. (c) Furthermore, as they see it, these harms are not offset by any benefits, because no effective treatment is available.

Starting in the late 1990s, policy makers and other authors who discuss this matter in the literature have taken remarkably similar positions that differ only slightly from the earlier stand of the genetics community. In fact, those recently writing on this issue have been so consistent in these views that we can count their conclusions as representing an emerging consensus (7–11). In their articles, Cohen (5), as well as Robertson and Savulescu (6), make several telling points. They note that the same hypothetical considerations can result in harms or benefits, that parental authority is an additional important consideration, and that hypothetical harmful outcomes are neither likely enough nor serious enough to justify overriding parental authority. Nevertheless, Cohen, as well as Robertson and Savulescu, conclude that geneticists should only comply with parental requests to test mature children (12–14 years old) who have demonstrated understanding of the tests and their implications and who also want the information (i.e., assent to testing).

What is now commonly recommended is that a decision on testing by the geneticist should be based on the facts of the particular case. In response to a request for testing a minor, and before agreeing to provide the test, a geneticist should begin with an assessment of the minor's compe-

tence to make the testing decision for her/himself, compare the benefits and harms of testing, and use that information in deciding whether the testing should be performed. The popularity of this reigning view among clinicians is documented in a report on an international survey conducted by Rony Duncan and colleagues that is described in a 2005 publication in *Genetics in Medicine* (12). Although this approach seems reasonable on its face, I shall be arguing that this consensus position is not justified.

Problems with the Reigning View

Regardless of the genetics community's comfort with their conclusions, and the pediatric community's consensus (13) that

> testing in childhood inappropriately eliminates the possibility of future autonomous choice by the person and risks stigma and discrimination. Unless there is anticipated benefit to the child, pediatricians should decline requests from parents or guardians to obtain predispositional genetic testing until the child has the capacity to make the choice,

a careful examination of their arguments shows that each of their three justifications for restricting testing is flawed. (A) Their autonomy-based justification for not testing children derives from a misunderstanding of the concept of autonomy. (B) There is little or no evidence supporting the postulated harms that are invoked to justify reigning policies. (C) Relevant evidence actually suggests that pediatricians and geneticists would benefit patients and their families by early testing of at-risk children and sharing the results. Together, these considerations suggest that geneticists should generally encourage early predictive testing of children and early communication of test results to the child in an age-appropriate way, although there might be a very few "clear-cut and exceptional circumstances" that could justify not testing in a particular case. I shall explain these thoughts one by one.

A. Autonomy-Related Concerns

Autonomy is the ability to govern oneself and guide one's actions by one's own commitments, goals, and values. Clearly, young children do not have this ability, so the autonomy of a child who lacks decisional capacity cannot be violated by testing the child without consent or assent. We recognize that autonomy is not at issue in medical decisions made on behalf of children whenever doctors and parents impose vaccinations, antibiotic injections or other treatment on children who may scream their opposition.[1] Those who oppose genetic testing of children do, however, argue that parental requests for tests should be rejected because testing a child who lacks decisional capacity violates the principle of respect for autonomy by denying the future adult the opportunity to make the choice for her/himself. They argue that if the child's genetic status is not tested and determined, then the future adult will have the option of deciding about testing.

This line of reasoning misses the most crucial factor in the decision. The child will be raised within a family that shares the experience of the genetic disease.[2] Family members are afflicted, they suffer the disease burdens, and they share their worries about how the disease will progress and their dread of which additional loved ones will succumb. That environment is an unavoidable piece of the child's inheritance. The decision as to whether to raise the child with knowledge or ignorance of her/his genetic status is one that the family must make. Either the testing is not performed and the child is raised without the family and the child having information about whether or not the child has inherited the mutation, or the testing is performed and the family raises the child in the context of knowing that the child has or has not inherited the mutation. Logically, there are no other options. And no child can avoid living through and being affected by the atmosphere in which such a decision needs to be made.

During the period when others must make decisions because the young cannot do so for themselves, those who are responsible for the well-being of children must make decisions on their behalf that reflect altruism rather than self-interest or irrational emotion. If there is a significant difference in the mental health implications of one course over the other, then the promotion of better mental health would be an important reason for parents to choose that course. In the situation of deciding about whether or not to pursue genetic testing of a child for an adult-onset condition, those who choose to leave the decision to the future adult are also actually choosing the course of raising the child in a cloud of dread and uncertainty about their genetic status. That, in itself, is a clear and certain harm.

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[1] Although those who hold the reigning view might invoke imminent risk to justify medical treatment and some vaccinations that they see as a violation of patient autonomy, the justification does not work when the low prevalence of an infectious disease makes contagion and risk unlikely.

[2] Adopted children will be the obvious exception.

Confidentiality is another autonomy-related concern raised by those who defend the consensus view. They argue that testing children for a genetic mutation violates confidentiality. It is true that confidentiality is a vital precept of medical ethics. It is a promise that the health care provider will not disclose information that has been shared under the expectation that it would not be divulged to others without the patient's explicit permission. Confidentiality is critically important in clinical medicine because it encourages open dialogue with health professionals, and because without the assurance of confidentiality health professionals would be less likely to accomplish the good that they aim to achieve on behalf of their patients.

Yet parents' obtaining their child's genetic test results does not violate the principle of confidentiality. When a young child is tested for a genetic mutation, the child is not choosing to conceal or reveal a secret. There is no disclosure of information that the child would only have given up under the promise of confidentiality. Parents decide to authorize taking a sample of their child's blood and having a laboratory perform genetic tests as parents typically authorize such procedures for medical purposes. Also, it is, and should be, standard practice for parents to be provided with medical information about their children, because they need to use it in making decisions about their children's health and well-being. Although one can imagine that some future adults might be unhappy that their parents know about their genetic status, parents' obtaining that information as the result of a test performed in childhood does not involve any violation of confidentiality. Talk of violations of confidentiality in the context of pediatrics may sound significant, but, again, it betrays a misunderstanding of the concept, and in this context it is a "red herring."

Parental authority is the model for making medical decisions on behalf of children. This is a well-accepted social norm that is supported by our laws, and it is usually the most appropriate mechanism for making decisions on behalf of children. Parents are typically deeply concerned with their children's well-being. Parents usually know their children best, at least better than most unrelated policy makers or medical practitioners. Parents also know themselves best. This consideration is important, because it enables parents to incorporate personal knowledge of their own skills, resources, and limitations into their decisions. Also, parents shoulder a very significant portion of the physical, economic, moral, and emotional burdens of the consequences of their decisions. Since they, far more than health care providers or policy makers, are the ones who will be living with the repercussions of their choices, the judgment should be theirs. Furthermore, in situations where different reasonable people can make different decisions, the parents' decisions are most likely to reflect values and priorities that the child will share (14). Overriding the decisions of attentive, caring parents who have decisional capacity can only be justified by "clear-cut and exceptional circumstances" such as avoidance of a very likely and significant harm.

B. Harms

The genetics community lists the "unbearable certainty of knowing," damage to self-esteem, survivor guilt, and injury to the family dynamics as harms that are consequent to genetic testing of children. Although there are differences between children and adults, the evidence at hand is that when adults are tested, regardless of the result and after a relatively brief period of adjustment, they are not harmed by having the information (15, 16).

Recently, Duncan et al. did a survey of clinical geneticists, to muster evidence for such psychosocial harms among children, because, according to their survey of the literature, no previous studies had documented such outcomes (12). They reported on 301 responses between June and September 2003 to their web-based questionnaire; the responses provided details of only 49 cases in which the testing of minors had been performed. Defining "adverse event" very broadly as "any outcome that is potentially negative for the individual involved," they noted that "in three cases parents experienced clinically significant anxiety related to how they would pass on information to their gene positive child." The other two reports of adverse events were experienced by two of the 26 mature minors who received test results. A 17-year-old male who was told that he had an increased risk for HD displayed "initial depression and rebellion but eventual acceptance." A 17-year-old female who was told that she had a decreased risk of HD showed "no psychological disturbance but worry and responsibility for affected mother and untested brother."

Not to diminish or discount these discomforts in any way, it is, however, important to remember that it is common and reasonable to consider untoward effects in the context of beneficial effects. The upset and discomfort of the vaccinated child is evaluated in the context of the immediate and distant risks and pains that are prevented for that child and for others. And in comparing positive and negative outcomes we have to recall the kinds of lessons that Jeremy Bentham taught long ago, and avoid oversimplified calculation (17). There can

be important differences in the certainty of the outcome, the intensity of the reaction, the duration, the likelihood of it being immediately combined with some additional positive or negative outcome, or being followed by other positive or negative outcomes. We have to consider the likelihood and extent of positive outcomes in order to justify foreseeable negative outcomes. If there are no direct positive psycho-social outcomes of testing children for an adult-onset genetic disease, then a small risk of an adverse outcome has to be considered in light of the importance of defending parental discretion. That said, the adverse events reported in the Duncan study hardly amount to harms that are significant or likely enough to justify a policy that denies testing.

Nevertheless, the most significant finding of the Duncan study is that clinicians continue to endorse the testing guidelines. There is a further result that can be gleaned from the study that the authors do not seem to notice. Although the survey was sent (and re-sent) to clinical geneticists in the US, the UK, and Australia, the anonymous respondents reported only 22 cases of the testing of immature children and 27 cases of the testing of mature children. These very low numbers of tests suggest that, to a very significant extent, the guidelines have become a standard of care. They actually govern the behavior of clinical geneticists and they inhibit the testing of children. This result in turn raises the question of whether medicine is justified in adopting a standard of care that is not supported by evidence.

Furthermore, we know that children and their families can and do cope with tragic genetic information without being devastated by the news or overcome by the burden. Children adapt to obvious familial disorders, such as hemophilia, that may afflict them in childhood. Children with terrible and handicapping conditions, such as paralysis, diabetes, or epilepsy, are also able to accommodate to that information. In that light, it is reasonable to ask whether the "unbearable certainty of knowing" is a credible concept or a genuine harm that should count as a reason for refusing to provide genetic testing. Again, children can and do cope with serious and even fatal diagnoses of diseases such as cancer, end-stage organ failure, and AIDS.

Affective Forecasting, Durability Bias, and Focalism

The fact that the genetics community has, without supporting evidence of harms, adopted, supported, and adhered to its strong policies on testing children invites speculation. Recent work in cognitive psychology on unwanted and invisible influences on judgment provides important insight into this peculiar phenomenon. A series of papers by Timothy D. Wilson and Daniel T. Gilbert and colleagues offer a framework for making sense of the genetics community's position (18–22). Although they take circumstances such as predicted reactions to football games, elections, and tenure decision as their examples, their points are relevant to any situation where decisions are based on predicted reactions.

Through a number of studies, Wilson, Gilbert and others demonstrate that judgments of future mental states are contaminated by various distortions (18–22). People systematically focus primarily on the negative reactions to a future event while largely ignoring other outcomes (focalism), including their ability to generate satisfaction with whatever outcomes come to pass, and they overpredict the duration of their negative emotional reaction to future events (durability bias) and hence reach unjustified and slanted conclusions about their own emotional responses to future events (affective forecasting) and to those of others (18–22). The robustness of these findings suggests that everyone is vulnerable to affective forecasting biases, including patients, parents of patients, and clinical geneticists.

Those who developed the policies on genetic testing of children for adult-onset conditions appear to have behaved just as Wilson and Gilbert would have predicted. That is, they probably focused their attention primarily on the possible negative emotional reactions following disclosure of testing results to a child or a family, and overlooked the advantageous outcomes, as well as people's natural ability eventually to reconstruct the outcome as something good. These normal cognitive distortions may have also led the drafters to over-predict the duration of the emotional reaction of children and their families and, in turn, inclined them toward untenable policy conclusions.

C. Unappreciated Benefits

The genetics community has asserted that genetic testing for adult-onset diseases provides no benefit to the tested child. But they may have overlooked possible benefits, and also some harms that could be averted by testing. As I have defined my topic, there is currently no beneficial medical treatment available for the conditions we are considering. Yet, other, non-medical advantages can be expected to follow from genetic testing and a variety of harms could be avoided by providing the tests.

There is accumulating evidence that uncertainty is worse than even bad news, and that the stress of uncertainty correlates with negative effects on the psycho-neuro-endocrine-immune system (23–26). For example, the vast majority of those tested for HD find the uncertainty of not knowing their genetic status to be more burdensome than receiving either a negative or positive test result (23–26). Similarly, children who have cancer cope better with specific and frank disclosure of information than with non-disclosure and uncertainty (26). From that perspective, almost everyone who is tested can benefit, at least by being relieved of uncertainty. Furthermore, in the examples listed above, 50–75% of those tested would also get the good news that they are unaffected. I take those odds alone to be an overwhelming reason for testing children.

Furthermore, other pediatric literature and policies acknowledge that deceiving or withholding information from children can be harmful (23–26). In fact, the American Academy of Pediatrics (AAP) has issued policies recommending that children be informed by the time that they enter school about their being adopted (27) and about their being HIV+(28). For example, the AAP position statement on adoption recommends that,

> Even before a child understands the words "adoption," "adopted," and "biological family" or "birth family," it is important that these words be a part of a family's natural conversation.… Families should be discouraged from "waiting until just the right minute" to tell children that they were adopted, because this may leave children feeling betrayed and wondering what else their parents may have hidden from them. Children may also learn information from peers or neighbors, which may impair the trust between parent(s) and child. It is important to share with even very young children their adoption story.… An honest approach in the discussion...will give a child permission to ask questions or to make statements about adoption and at the same time will take away the veil of secrecy that often implies that being adopted is a negative condition.

Similarly, the AAP has endorsed a policy of informing children that they are dying (29). And in a similar vein, authors such as McGee et al. (30) and Haimes (31) have argued that children should be told that they were created with gamete donation as soon as they are able to understand. These positions are based on compelling reasons that are also applicable to the case of genetic testing of children for adult onset diseases.

Generalizing from what we already know about these analogous situations, we can expect that withholding testing can be harmful. We can also surmise that testing early and informing children of test results can prevent problems that are likely to arise from delaying testing until the children are old enough and mature enough to make a decision for themselves. There are some general considerations for testing and informing children that apply to many situations:

- When all of the adults involved know that a child is at risk, non-disclosure creates an environment of tension and discomfort that the child is likely to pick up and translate into a sense of insecurity. Learning the information early on is likely to avoid these problems.
- Information becomes part of identity. When a child learns personal genetic information early in life, it can be absorbed and accommodated into identity. When the information is disclosed later in life, it can be jarring to identity and very hard to internalize and accept.
- Putting off the testing decision until late adolescence compels the child to live through many years of uncertainty. It also pushes off the testing decision and its consequences into adolescence, compounding the trauma of those years.

Additional considerations for the parents and for the child are especially relevant to genetic testing for adult-onset conditions. Delays in learning a child's genetic status prolong parents' uncertainty and anxiety. From surveys of parents, we know that they identify worries about when and how to tell a child and anguish about the aftermath of the conversation as a significant burden. Delays in testing increase their dread of having to speak about the matter with their child, and that makes the hurdle of latter disclosure seem more and more formidable. The prolonged period without testing also delays their learning how to speak frankly about the genetic condition. When parents begin speaking about it when the child is very young, they have the chance to become comfortable with the discussions as the child matures.

Putting off testing until the child reaches late adolescence can also be expected to have a negative impact on the child. The delay amplifies the dread and increases the hurdles for the child who anticipates developing a familial disease, and these magnified impediments set the stage for a crisis when the information is ultimately disclosed. Refusing testing to children also delays the child's

learning to speak about her/his condition and accommodating to it. Avoiding these formidable and likely harms to parents, children, and their relationships amounts to a significant benefit.

Evidence from adult testing for HD provides a further consideration that is relevant to assessing the benefits of early testing. Only 10–15% of at-risk adults opt for Huntington's disease genetic testing. Studies of those who were tested provide relevant and important data. Some untoward results followed reports of both good and bad news. People were upset, but over time, most did come to accept the information and most were glad that they were no longer in ignorance. People also behaved as affective forecasting would have predicted. Because people tend to exaggerate the impact of bad news, many of those who did not know their HD status before testing had acted as if they would develop the disease, and they had made choices about reproduction, finances, education, and career in that light. In other words, they had made decisions and foregone opportunities as if they were certain to develop the disease. I take this as a very significant and avoidable harm. If it can be averted for 50–75% of the children who are at risk for inheriting a serious genetic disease, it is important to amend policy in that light.

Conclusion

Geneticists often state the principle that we are an amalgam of our genes and our environment. In other words, the adult someone ultimately becomes is the product of both her genetic inheritance and the conditions and influences of her life. While there is currently nothing that we can do to alter someone's genetic endowment, we can take steps to modify the environment in which a child is raised so as to optimize her accommodation to her genetic heredity and diminish the risk of confounding the problem. The possible benefits of doing so make it ethically important to avoid psychological traps and make policy decisions about genetic testing of children based on available information and sound reasoning.

An important principle in ethics is that honesty is usually the best policy. Another is that knowledge is usually better than ignorance. Both of these precepts are obviously applicable to the question of whether children should be tested for adult-onset genetic disease. They point to the conclusion that such testing should be done.

In addition, the arguments that have been advanced to oppose testing seem unpersuasive when they are carefully examined. (A) The appeal to autonomy is baseless and confused. (B) There is no evidence of harm from disclosure. And (C) the claim that there are no benefits to be had from early testing and early informing is based on an unjustifiably narrow view of benefits that actually ignores factors that the AAP considers very significant in other contexts.

All of these factors, taken together, lead me to a conclusion that is diametrically opposed to the policies and guidelines of the genetics and pediatric communities. Based on the considerations I have outlined above, and the models of well-reasoned position statements on similar issues of testing and disclosure, I conclude that pediatricians and geneticists should encourage parents to pursue genetic testing of children at a young age. They should also strongly recommend the involvement of genetic counselors for the education and support that they could offer. Furthermore, they should strongly advocate for early disclosure of test results, show understanding of the anticipatory fear that parents are likely to experience, and provide guidance to help parents learn to speak openly with their children about their genes. Ultimately, however, because parents are in the best position to assess their own emotional state and ability to cope with the test results, because of the social importance of yielding to parental discretion, and the fact that the future is long, I would advise doctors to leave the actual decision to parents.

The fact that so many thoughtful and well-intentioned authors of medical policies have reached erroneous conclusions on this issue tells us that the power of affective forecasting makes it very hard to see the light. Pediatricians and geneticists should encourage reluctant parents to have their children tested—and then accept the parents' decision.

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