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CLINICAL CASE

Presymptomatic Testing of Children for Huntington's Disease

Commentary by Robert Klitzman, MD, Roberto Andorno, JD, JSD, and
Leon Dure, MD

Dr. Carpenter had taken care of 3-year-old Josh since he was born. One afternoon, Dr. Carpenter received a call from Josh's parents, both of whom were successful professionals. Josh's dad had just been diagnosed with Huntington's disease, a degenerative, neurological disorder, and the parents wanted Josh to be tested for the disease. The genetic polymorphism for Huntington's is autosomal dominant, so Josh had a 50-50 chance of inheriting the gene from his father, and, if he did, he would develop the disease if he lived to middle age.

After offering her condolences to Josh's parents, Dr. Carpenter expressed what she considered to be a consensus opinion on the matter: "At present, there is no prevention, treatment, or lifestyle change that has an effect on expression of the gene. For these reasons, pediatric and genetic medicine specialty societies advise against testing children. Josh will have plenty of time to decide whether he wants to be tested once he is an adult."

"I disagree completely," said Josh's mom. "If Josh grows up knowing he has this condition, he will be much better prepared to deal with it as an adult. He'll be forming his identity over the next 18 years. Assuming he has the disease, he won't face the trauma of having his identity and life plan change all at once."

"But you'll be denying him the chance to make the decision as an adult," replied Dr. Carpenter. "Maybe he will decide not to know."

"Isn't that what parents do?" said Josh's dad. "They make decisions for their children. If we take your approach, Josh may be 25 when he discovers that he wishes he knew all along whether or not he has Huntington's. But he won't have that option because of our decision not to test him. The choice to do nothing is still a choice, Dr. Carpenter."

Commentary 1

by Robert Klitzman, MD

Josh's case raises several complex and important issues at the intersection of medicine, psychology, and ethics. His parents argue that it is their right to decide whether Josh should be tested, saying "Isn't that what parents do? They make decisions for their children." Yet, in fact, parents do not always do so. Parents do not

decide, for example, how their children will vote in elections once they turn 18. So, too, in this case, this decision is one best made by offspring after they are adults.

Several medical facts about the disease are highly relevant to the case. Huntington's disease (HD) is a fatal autosomal-dominant disease with adult onset (usually when the individual is in his or her 40s or 50s) that causes several neurological and psychiatric symptoms. To date, no effective treatment exists.

Most patients have seen the devastating effects and lethality of the diagnosis in a parent. To learn that one carries the mutation can cause psychological distress and trauma, in part because there is nothing that can be done to stop or prevent the disease.

An adult may nonetheless decide to undergo testing. Such information could potentially inform decisions of whether to have children or pursue lengthy years of graduate school. Some at-risk individuals, particularly those who are health care professionals, may want to know, since they feel relatively more comfortable with such diagnoses and prognoses, having treated patients who confront these dilemmas.

Yet, not surprisingly, most at-risk individuals decide against testing. The prospect of finding out that one has an untreatable lethal mutation and having to decide whom then to tell are simply too frightening [1, 2]. Given the intensely personal nature of these preferences and decisions, standard medical practice is to recommend that individuals contemplating this decision meet with trained genetic counselors to discuss the difficult pros and cons at length.

Ethically, the principle of respect for autonomy dictates that individuals make these decisions for themselves. Thus, an adult may decide to get tested. But a parent's right to exercise autonomy does not necessarily extend to decisions about his or her children. Arguably, a mutation-positive HD test result can harm more than help a young child. Hence, for a parent to test a child may violate principles of beneficence and nonmaleficence—i.e., benefits to an individual should be maximized, and harms minimized.

Of note here, Dr. Carpenter says that the parents would be denying Josh the opportunity to make the decision as an adult. Dr. Carpenter could perhaps have argued that the parents' decision may in fact cause stress, anxiety, and depression for Josh. Children do not fully understand death and disease. With emotional and cognitive development, individuals gradually become better able to cope with such stresses. A child's difficulty understanding and responding to the stresses of serious disease and death can lead to behavioral problems, and "acting out" (e.g., becoming involved in drugs).

In essence then, the critical conflict is not between the rights of the parents and the paternalism of the physician, but between the rights of the parents and the rights of the child. The parents' decision affects a third party—Josh. Dr. Carpenter must

follow the principles of beneficence and nonmaleficence and decide what is best for Josh—what will potentially produce the most benefit and the least harm for him. These principles lead to a recommendation not to test Josh, which conflicts with the parents' views of their rights to decide for him. In weighing these competing sets of principles, however, beneficence and nonmaleficence for the child outweigh the parents' underlying claim of autonomy. From a utilitarian perspective, the overall harm of testing outweighs the potential benefit to the parties involved.

These issues might be viewed differently if key aspects of the disease were different. For example, if disease symptoms appeared in childhood and an effective treatment existed that could then be started, testing would offer clear benefits to the child, and failure to test and treat the child could in fact be harmful. Presumably in such a case, the physician would recommend testing and agree with the parents, and problems would occur if for some reason the parents opposed testing, saying that they did not want their offspring to know. Indeed, such a conflict pitching the rights of the parents against those of the child occasionally arises in the case of HIV, where late adolescents who were infected at birth need treatment, but the parents do not want to tell the adolescent that he or she has HIV in part because they feel embarrassed and ashamed at having infected the child. Many physicians believe that if the adolescent is 16 or 17 and becomes sexually active, the benefits of disclosing the diagnosis outweigh the benefits of respecting the parents' autonomy, in part because the adolescent is more likely to transmit the virus to a sexual partner if he or she does not know about the diagnosis [3].

Similarly, if a genetic disease has adult onset, but effective treatment is available that could be advantageously started in childhood, testing would benefit the child. If effective treatment were available, physicians would recommend testing, hoping the parents would agree.

Josh's case asks whether a doctor has a right to oppose a family's values, but that conflict does not appear to be the critical one. Physicians have a professional responsibility to "first do no harm," and I know of no established religious or cultural tradition that would support the parents in the present case, given the ratio of potential harm to potential benefit involved in testing the child.

Physicians can attempt to address and resolve their disagreement with the parents by discussing the issues with them and presenting the ethical arguments against testing.

At some point in the future, parents and clinicians will face dilemmas of whether to avoid these decisions altogether by using nondisclosing preimplantation genetic diagnosis. In this procedure, a physician screens embryos for HD and other mutations, and implants only mutation-negative embryos without informing the parent at risk whether any mutation-positive embryos were in fact found. In this way, a parent who is at risk (i.e., has had a parent with HD) can have a child without the mutation while avoiding having to confront the stress of knowing his or her own HD status or having to decide whether to test a child [4].

Genetic markers are being discovered for a growing number of disorders, and direct-to-consumer marketing of these tests has begun. Hence, rising numbers of patients may either ask physicians about the value of such testing or undergo testing and then ask physicians to interpret the results. Thus, physicians will need to know how to approach such complex decisions. Doctors will need to be able to offer assistance in judging the pros and cons of genetic testing to both adult patients and their offspring.

Many of these decisions raise complex challenges due to scientific uncertainties and patients' varying psychological needs and desires. In many regards, HD is unique. Most diseases are not autosomal dominant, lethal, and without treatment. Rather, most common diseases appear to involve multiple genetic and environmental factors, and the relative contributions and roles of these genes in causing such diseases vary widely. For example, the so-called BRCA 1/2 mutations for breast cancer account for approximately 10 percent of all breast cancer, and the presence of a mutation results in disease about 40 to 60 percent of the time. Whether a patient should take this test is a highly individual and subjective decision.

Parents may want to test their children for other conditions for which tests exist, but effective treatment does not. Or a treatment may offer a small amount of possible benefit, while testing may again potentially cause some harm. Physicians then have to weigh a possible small benefit against a possible harm. These decisions entail uncertainties, subtly, and nuance, and physicians will need to feel comfortable confronting such choices.

Ideally, in all of the above genetic scenarios, doctors should refer patients to genetic counselors for assistance as needed. Unfortunately, the United States and other Western countries have severe shortages of genetic counselors. Many physicians do not know of a genetic counselor to whom they can refer patients. Thus, doctors will need to find some way to address these issues and feel comfortable doing so.

In coming years, scientific understanding of genetics will surely continue to mushroom, posing critical medical, ethical, and psychological challenges for which clinicians will need to be prepared. This preparation will help Josh, his parents, and countless others who face these conundrums.

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Commentary 2

by Roberto Andorno, JD, JSD

Huntington's disease (HD) is a hereditary neurological disorder that leads to serious physical and mental disabilities. Initial symptoms usually appear between the ages of 35 and 50 and may include difficulty in concentration, memory loss, depression, and uncontrolled muscle movements. As the disease advances, uncoordinated movements become more apparent, and the decline in mental abilities generally results in dementia.

Presymptomatic genetic testing is available to determine whether a person has the faulty gene that causes HD. Every child born to a person who has the disease has a 50 percent chance of inheriting the faulty gene. If the mutation is present, the person's risk of developing the disease is virtually 100 percent. At present, there is no cure for HD, and there is no known way to stop it from progressing.

The foregoing case presents a conflict between a child's parents and the child's doctor regarding the advisability of performing genetic testing on the minor for Huntington's disease. The parents want the test to be performed on the grounds that their son, Josh, will be better prepared to cope with the disease if he—and they—know from an early age that he will develop it sometime during his lifetime. In contrast, Dr. Carpenter does not want to order the test, arguing that Josh should not be deprived of the opportunity to decide for himself at a later age whether or not to be tested and potentially receive such harmful information. So, who is right? Is Dr. Carpenter interfering with the parental control of Josh or simply committed to his best interests?

What Is Best for the Child?

For adult patients, the choice to have genetic testing is a very personal decision that, in general, should be respected by health care professionals. This is clear when the result of such testing can be clinically useful medical information. But even if there are no preventive or therapeutic measures available (as it is the case for most genetically related diseases), a case can be made for taking the test and being told the results. Certain studies indicate that some people prefer to be tested for HD and to know the results of such testing because they feel that the relief of testing negative would outweigh the possibility of testing positive. Some feel that in such a situation nothing is worse than uncertainty [1].

But when children are considered for genetic testing for Huntington's disease, there are additional concerns that weigh against the reasonableness of testing. In the United States several medical bodies have issued statements advising their members that presymptomatic genetic testing of children for diseases usually manifested later in life, and for which there is no prevention or cure, should be strongly discouraged [2-4]. The main arguments supporting this position are, (1) the absence of a clear medical benefit to the child; (2) the psychological harm that the child may experience as a consequence of his or her parents' knowledge of the test results; and (3) the preservation of the minor's right to make an autonomous decision in the future. Moreover, testing of children for HD may expose them to discrimination or stigmatization and even result in deteriorating sibling relationships [5, 6].

At the international level, the widely accepted view is similar to that in the United States: all major guidelines on the matter strongly discourage genetic testing on children for late onset disorders [7]. The vast majority of clinical geneticists in a number of countries, including the United States, agree with the existing guidelines [8].

The Child's Right Not to Know

An additional argument against the testing of children for late onset disorders is the preservation of the child's right not to know. The right not to know one's genetic information is increasingly recognized by international and domestic regulations as a response to the growing availability of genetic tests, which may burden people with more information than they can bear. This new right can be regarded as a legitimate expression of personal autonomy, although its ultimate foundation is people's interest in not being psychologically harmed by such potentially devastating information about their health status [9]. It is indeed unjustifiable, or even inhumane, to take away hope from people by exposing them to knowledge they do not want, especially when there is no treatment [1, 10].

If one accepts that adults have a legitimate interest in not knowing their genetic information and continuing their lives in peace, then it seems fair to preserve children's right to choose until they can decide for themselves whether their life is better lived with that knowledge or without [11]. In other words, allowing children to be tested for late onset disorders compromises their future autonomy [12]. Support

for this conclusion comes from empirical studies in which only about 20 percent of people at risk for Huntington's disease decide to undergo the testing [13]. If the vast majority of adults prefer not to know whether they will suffer from HD or not, how can we assume that a 3-year-old boy would benefit from such devastating information? Should we not rather try to preserve in such a case what Feinberg calls "the child's right to an open future" [14]?

Conclusion

Parents generally have the legal authority to consent to genetic testing of their children, and in doing so they are expected to make the best decision for the child. Health care professionals, however, have an ethical and legal duty to intervene in a minor's interests if the parental request for a test may harm the child. In this case, Dr. Carpenter is not improperly interfering with the legitimate rights of the parents to make decisions on Josh's behalf. He is simply keeping to the widely accepted recommendations of professional bodies that state children should only be tested when it is in their interests and some treatment can be offered, and that they should not be tested for late onset disorders.

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Commentary 3

by Leon Dure, MD

This clinical case is particularly relevant for at least two reasons. First, the development of greater awareness of genetic testing for specific diseases by the public requires that clinical care professionals be knowledgeable not only about the types and meanings of tests, but also of the consequences of obtaining such tests. Secondly, there are significant ethical issues that are brought to light by this case, especially as they relate to genetic testing of minor children.

Physician's Perspective

Dr. Carpenter is essentially correct with respect to her interpretation of professional guidelines for testing of minor children at risk for Huntington's disease (HD). Both lay and professional organizations in the United States, Canada, and Europe recommend that testing of asymptomatic children await an age at which the child's consent can be reliably given [1-3]. Justification for this policy comes from the fact that there is no cure, nor are there any proven lifestyle modifications or treatments that can delay or alter the onset and course of the condition. Thus, from a health care professional's perspective, it can be argued there is no medical reason for obtaining the test. This does not imply that testing may only be offered when a child meets an "official" age of consent, depending on a state or country's definition, but at the very least it indicates a preference that children exhibit some understanding of the test and its consequences. An emancipated minor, for example, could undergo testing. An important distinction is made in the case of symptomatic testing—a child with clinical symptoms of early-onset or juvenile HD. Here, testing is often entertained as a means of identifying a particular diagnosis and avoiding further invasive or intrusive tests. In this case of a healthy 3-year-old, however, such reasoning does not apply.

Another point from Dr. Carpenter's perspective is the identification of Josh as the patient. Practicing physicians who care for children rely on parents to collaborate on decisions relating to health care. Tensions can arise, however, when parents'

motivations or decisions are at odds with those of a child's caregivers. Such conflicts commonly occur in the context of scheduled vaccinations in childhood, and parent-driven requests for genetic testing may develop into a similar problem. Despite these potential areas of disagreement, physicians must acknowledge their duty to a patient and act accordingly.

Parental Perspective

The parental viewpoint touches on ethical issues that are unique to medical care of children. Parents are considered surrogate decision makers for their children, as minors are for the most part considered unable to make independent health care decisions [4]. It must be noted that children are distinct from other populations with impaired decision-making capacity, notably individuals who, by virtue of an injury or condition occurring early in life, will never develop competence and individuals who may have lost the ability to make decisions through injury, aging, or disease. Children, on the other hand, are considered "precompetent," in that they are expected to develop the resources and capabilities to make independent health care decisions. As a general concept, the goal of health care decision making is to ensure an open future for children by preserving as many options as possible for the time when they develop into competent individuals and members of society.

In this case, the parents state their conviction that, should Josh test positive for Huntington's disease now, he would be better prepared and have more time to accept the diagnosis. Moreover, the parents assert that they know best and have the right to make decisions for Josh. The conflict pits parental autonomy against the potential threat that testing for HD could have on a child's open future.

Prevailing Views

Most professional organizations argue that testing for Huntington's disease and the determination of a positive test (meaning possession of the mutation for HD) would imperil the open future that is the ideal for a child. Consequences of a child's testing positive for HD could include stigmatization, discrimination, damage to self-esteem, and perhaps limitations on educational and other pursuits that might be enjoyed by any other individual.

Because specific data on children is sparse, it is informative to consider how adults have responded to genetic testing for HD. Overall, it is estimated that only 10 to 20 percent of at-risk individuals undertake presymptomatic testing for HD, despite availability of the test since the mid-1990s. Adults have reported a number of concerns about the consequences of testing, ranging from obvious fears of discrimination by insurers to less-tangible concerns regarding how testing could be communicated to other family members [5, 6]. Interestingly, the issues of communication arise regardless of the test results. The fact that a minority of eligible adults undergoes genetic testing despite ready access suggests that any particular child would have a fairly high likelihood of refusing testing after attaining adulthood. Testing a child would thus restrict choices that would be available in adulthood.

Critics of this view point out that there is little evidence to substantiate these concerns [7]. Moreover, they argue that testing of a minor child has a 50 percent chance of indicating no risk of HD and that withholding such information could have deleterious effects. As is true of the converse, this contention suffers from minimal supportive evidence, leaving health care professionals to navigate the course themselves. One approach has been to consider the best-interest standard, a construct that is very much in line with the societal goal of providing an open future to children [8]. When this standard is applied to the issue of childhood testing for HD, it is clear that, by refusing to test, the clinical community is exercising a duty to foster a best interest. Parents acting as surrogate decision makers for children also may have the same motives. Given the general acceptance of professional guidelines, though, it is apparent that physicians who care for children consider the risks of HD testing to outweigh potential benefit.

Clinician's Response

So, what should Dr. Carpenter do? A compromise approach would be to investigate how the family is coping with the father's new diagnosis of HD. Dr. Carpenter should attempt to understand each parent's perspective of genetic testing and determine whether there is any particular conflict between their views. It would be important to establish whether the family plans to tell Josh, and when. Even critics of professional guidelines have indicated that the reason for testing is to have an open exchange of information and to share this information with the child and other family members. Given that Josh is a toddler, every effort should be made to convince the family that testing should be done when he is more mature.

Finally, it must be noted that many of the concepts and ideas regarding childhood testing for HD derive from the fact that there is little data relating to the attitudes of testing in childhood, nor is much known about how families typically tell their children about the disease. There is some evidence that people who have been tested while still minors have experienced both negative and positive consequences, but available data is not without controversy [9-11]. Research has only recently examined patterns of information transmission in families [12]. With respect to risk of HD, these data indicate that children are not informed early on about their own risk of disease and are typically not given such information until the second decade. Therefore, Dr. Carpenter should work to educate Josh's parents about developing a long-term plan regarding how they could approach genetic testing, emphasizing the reasons for a judicious approach. Much of the basis for a disinclination to test is that HD has no cure and no effective treatment. If, on the other hand, a rational treatment strategy is developed for HD, the balance of arguments for and against testing will change dramatically.

This case illustrates a number of significant tensions not only within the medical community but also between physicians and parents of minor children. A final word to the reader: physicians must be clear that, in this case, the child is the patient, and a best-interest standard may be in conflict with parental wishes.

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