Can children and young people consent to be tested for adult onset genetic disorders?

Donna L Dickenson

Department of Primary Health Care and General Practice, Imperial College of Science, Technology and Medicine, London W2 1PG

Donna L Dickenson, *Leverhulme senior lecturer in medical ethics and law*

d.dickenson@ic.ac.uk

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What should we do about children and young people who want to be tested for incurable, adult onset, genetic disorders? In particular, what should a general practitioner do if he or she believes the young person is competent to decide, but the regional genetics unit refuses to test anyone under 18? In this article I discuss such a case (drawn from actual practice, but anonymised), and consider the arguments for and against allowing the young person to be tested in terms of good practice, case and statute law, empirical evidence, and ethics.

Summary points

- Existing case law allows competent young people under 18 to consent to testing for adult onset genetic disorders
- Many clinical genetics units operate a bar at 18
- Genetics units and referring general practitioners need to think whether they are being paternalistic in denying the test to a competent minor
- Each case should be considered on its own merits, taking into account the seriousness of the disorder and balancing that against the emotional and cognitive competence of the young person
- This approach is consistent with new guidelines

Case study

Consider the following case. As a general practitioner, you are confronted with Alison, an intelligent 15 year old girl whose father has recently tested positive for Huntington's disease. His own mother died of the condition before Alison was born. Alison wants to know whether she too will develop Huntington's disease. Her parents, who have accompanied her to the surgery, support her wish. Alison's mother is herself contemplating genetic testing for the BRCA1 gene implicated in some breast cancers, because her mother and elder sister died from the disease. You know that the clinical genetics unit serving your patients will not test anyone under 18, although Alison can have counselling. You point out that according to the unit's careful protocol even those over 18 must undergo counselling before having the test. Alison thinks this over and replies, "I can see the point of having some talks with the counsellor first. But if I do decide I want it, do I still have to wait another 3 years before I can actually have the test?"

The anomaly

Many regional genetics units are evolving policies which do take young people's requests seriously. However, in the wake of new policy recommendations from the royal colleges, the Nuffield Council,[1] and the BMA,[2] it would still be unusual for a request like Alison's to be granted where the disorder is as serious as Huntington's disease. I believe that the situation is anomalous in the light of law giving young people under 18 the right to consent to treatment, including testing. The argument primarily concerns consent, but it is also important to note that an action in negligence could arise if Alison gave birth to a baby who was positive for Huntington's disease and whom Alison would not have had if she had known her genetic predisposition.[3]

Professional guidelines

Professional publications and guidelines on the predictive testing of children at risk have often focused on the situation in which parents request testing on the child's behalf, rather than the scenario in which the young person herself wants to be tested. In 1989 a research group of the World Federation of Neurology declared that children should not be tested for Huntington's disease on their parents' request. The age of majority remained the touchstone in the 1994 recommendations of a joint committee of the International Huntington's Association and the World Federation of Neurology Research Group on Huntington's chorea.[4] But the report added, "It seems appropriate and even essential, however, that the child be informed of his or her at-risk status upon reaching the age of reason."

In the same year, a working party of the Clinical Genetics Society concluded that although discussion and counselling could and should be offered to minors, "formal genetic testing should generally wait until the 'children' request such tests for themselves, as autonomous adults."[5] However, the working party did say that testing should wait either until the person

affected is adult or "is able to appreciate not only the genetic facts of the matter but also the emotional and social consequences."

The legal position

These documents mainly focused on younger children. The argument here is that the law already allows competent older children and adolescents to consent on their own behalf. There are two strands in this syllogism. Firstly, treatment includes diagnosis, and therefore consent to testing is considered under the same rubric as consent to treatment.[6] Secondly, the general legal principle that 18 is the age of majority was modified in the Family Law Reform Act 1969 to allow young people of 16 to give consent that would be as valid and effective as an adult's. Subsequent case law undermined the ability of young people under 18 to refuse consent to a procedure. In Re W, the Court of Appeal held that where someone with parental responsibility gave consent to treatment on the minor's behalf, the young person could not refuse.[7] However, both Alison's parents and Alison give consent, and the young person's right to consent was reiterated in Re W.

Alison is still only 15, while the dividing line in the Family Law Reform Act is 16, which was also the age of the girl in Re W. However, in the Gillick case (involving a 15 year old girl's consent to treatment) a function specific, flexible test of competence was set down.[8] This was whether the young person had "sufficient understanding and intelligence to enable him or her to understand fully what is proposed."[9] (This is assumed to be an English case, but in Scotland Alison would also probably be able to consent on the similar grounds that she had sufficient understanding of the issue to make a choice.[10]) Alison is likely to have a fuller understanding than many 15 year olds of what genetic disorders imply. She is like the children with chronic cardiac or orthopaedic conditions studied by Alderson.[11 12] These children had surprisingly high levels of familiarity with diagnostic procedures, cognitive sophistication about probabilities and prognosis, and strong personal values. Against "the child's right to an open future," we could argue that young people with a family genetic history like Alison's grow up fast.[13 14]

ANGELA SMITH

Harm, best interests, and paternalism

Another legal strand is the Children Act 1989. This introduced "the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding)" into the "welfare checklist" which must be used in any case affecting his upbringing.[15] The act also requires consideration of "any harm which he has suffered or is at risk of suffering."

Would a positive test inflict harm on Alison? Even if there is no possibility of treatment, there might be benefits in terms of control, ability to plan, and family solidarity. If this is true in Huntington's disease—a dreadful disease, with no cure and a relatively late onset—then it is all the more true of lesser conditions.[16]

Higher psychological morbidity in patients who test positive[17] must be balanced against the relief of uncertainty, even on learning of a high risk test result, reported in some studies of tests for Huntington's disease and breast cancer.[18 19] According to another study, "a high-risk result merely exchanges the uncertainty of whether Huntington's disease will develop for that of when it will develop."[20] However, Brandt found no greater psychological morbidity in patients who had been informed that they had tested positive than in those told they had negative status.[21]

Early expectations were that up to 75% of those at risk of inheriting the Huntington's mutation would choose to be tested in order to relieve uncertainty. However, fewer than 10% of people with a parent who is positive for the mutation have chosen to have counselling about the possibility of a test, and only two thirds of these people actually opt for testing.[22] So Alison's wish is unconventional. But one could argue that it may therefore be all the more personal and deeply considered; an "authentic choice" of the adult sort, which many developmental psychologists believe should be honoured in adolescents.[23 24]

Autonomy and paternalism

The Children Act also leaves scope for courts to find that the child's expressed wishes are not his "true wishes, those that serve his best interests."[25] Perhaps Alison's expressed wishes are not really her true wishes, but here we risk paternalistic condescension.[26] Paternalism usually favours treatment on the grounds of best interests, even in the absence of the patient's consent. Yet the paternalistic thing to do in Alison's case is not to override her refusal and impose treatment, but to override her consent and withhold the test.

Alison may seem too vulnerable to request testing, because of the very fact that she has recently learned that she is at risk for Huntingdon's disease. But we are all, by definition, vulnerable at the time we are asked to consent to treatment; we are generally ill or facing uncertain results about a possible diagnosis.

Another argument against allowing adolescents to be tested is that they are subject to family influence. Young people of 14 and 15 asked to make hypothetical medical decisions frequently deferred to what they saw as their parents' wishes.[27] But studies of adults might equally well show that they did what they thought their spouses or children would want. In Alison's case, where both she and the family agree, we must be particularly

careful not to impose a conflictual, individualistic model based on the premise that individual and family interests necessarily collide.

If the young person's values and identity seem reasonably coherent and secure, then her consent should be honoured. Conversely, identity only comes with making choices and having them enacted.[25]

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Commentary: Weighing burdens and benefits rather than competence

Gail Geller

Children and adolescents who are at high risk of future disease because of their family history are increasingly likely to be eligible for genetic susceptibility testing as we identify greater numbers of mutations that cause disease or a susceptibility to it. It is generally agreed that for some diseases, such as familial adenomatous polyposis coli, predictive testing during childhood can be beneficial.[1–7] In this case, early treatment can reduce morbidity and mortality in carriers of the mutation and eliminate the need for periodic surveillance of the colon in children who are found not to carry the familial mutation. For other disorders, such as familial breast-ovarian cancer and Huntington's disease, the lack of any effective treatment during childhood and concerns about psychological harm to the child have led to recommendations against testing children.[1]

Dickenson argues that competent adolescents who request susceptibility testing, even for untreatable diseases with onset in adulthood, ought to be allowed to have this. She believes that a "precedent" exists with regard to adolescent consent in the realm of treatment decisions, and that to disallow adolescents from consenting to susceptibility testing is legally anomalous and paternalistic.

It is not clear whether the benefits and burdens of susceptibility testing for adult onset disease are equivalent to those of treatment for a known disease or condition. Even within the rubric of susceptibility testing, it is not clear whether the standards for determining competence should be the same for untreatable and treatable diseases. In fact, in the case of susceptibility testing for untreatable diseases, we may want a higher standard of competence because it is less clear that the benefits outweigh the harm. The overriding question is not whether adolescents are competent to consent to susceptibility testing (indeed, many adolescents are more mature than adults), but whether the potential burdens of testing outweigh the benefits. Even with competent adult patients, practitioners often deny their requests for treatment where there is no medical benefit (for example, antibiotics for a cold), and they deny requests for tests where the psychosocial sequelae are as likely to be harmful as helpful (for example, false positive results when magnetic resonance imaging is used to investigate patients with a headache).

A weighing of the benefits and burdens needs to take several factors into account in addition to the child's level of maturity and the obvious psychological impact of such testing. Among them are the implications for ethical reasoning itself, the economic and social impacts, and how remote in time the onset of the condition is.[8]

From an ethical point of view, it is not clear why we would use different criteria for adolescent testing depending on who is making the request. In situations where healthcare decisions are made by parents or health professionals on behalf of minors, the seriousness of the disorder is usually balanced against the availability of an effective treatment. This is the basis for waiving the minimum age criterion for testing for familial adenomatous polyposis. The same ethical

Johns Hopkins Medical Institutions, 550 N Broadway, Baltimore, MD 21205-2004, USA
Gail Geller, *associate professor of pediatrics*
ggeller@welchlink.welch.jhu.edu

argument ought to underlie our response to adolescents who request predictive testing. It ought not be enough, as Dickenson claims, to balance the seriousness of the disorder against the emotional and cognitive competence of the young person, particularly if the disease in question is untreatable.

The economic implications are, to some extent, tied to the remoteness of the time of onset of the condition. Access to genetic susceptibility testing for minors is not an "all or none" decision. The issue is not whether to test the Alisons of the world at all, it is whether to test them now. So the question becomes: "Are there compelling justifications, ethical and practical, to wait until the adolescent reaches the age of majority?" In answering this question, consideration must be given to the problem of scarce resources, both economic and human. The healthcare system is not currently set up for the extensive counselling and assessment that is being recommended to assess the competence of adolescents who might request such testing.[9]

If, however, we design a research protocol intended to learn more about the impact of susceptibility testing on adolescents' lives, a part of which would involve implementing an extensive pretest assessment, then the social benefit would justify the added expenditure. The moral grounds for testing competent adolescents on a case by case basis, if done within a research context, become broader than either competence or beneficence.

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The World Bank and world health

Focus on South Asia—I: Bangladesh

Kamran Abbasi

This is the fourth in a series of six articles examining the World Bank's role in international health

BMJ, London WC1H 9JR
Kamran Abbasi, *assistant editor*
kabbasi@bmj.com

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The World Bank's policies may sound reassuring in Washington, but their true efficacy can be gauged only at country level. Each region (figure) offers differing challenges—from economic collapse in the Far East to economic infancy in central Asia; from perpetual poverty in Africa to the floundering aspirations of Latin America. Perhaps, of all regions, South Asia is the most enigmatic. Sri Lanka's healthcare system is relatively successful despite the ongoing civil war, whereas Nepal and Afghanistan lie at the other end of the spectrum. Somewhere in between—geographically, and in terms of health indicators—are Bangladesh, India, and Pakistan.

A sixth of the world's population is crammed into what was, until partition in 1947, a single nation. Bangladesh, India, and Pakistan may have common cultures, but in their short, independent lives they have acquired distinct personalities which require differing approaches from the bank (table). In Bangladesh, approximately 35% of health sector funding of the government is coordinated through a large consortium of donors and aid agencies, headed by the bank. In India, specific disease control, health, population and family planning, and nutrition programmes are being increasingly linked through state-wide health reform programmes. In Pakistan, by contrast, lending for health is dependent on the government introducing institutional reforms. The regions within each of these countries can present equally diverse challenges.

Richard Skolnik, the bank's sector leader for health, nutrition, and population in South Asia, believes that the region is unique: "This region is especially important given the very large numbers of very poor people. Our aim over the long term would be to assist our client countries in establishing coherent, effective, and sustainable approaches to health." Such approaches seem far off in an area that is struggling against malnutrition, especially in children, high

Summary points

The success of the World Bank's policies can only be truly judged in client countries

South Asia offers a useful insight into the bank's response to differing challenges in Bangladesh, India, and Pakistan

High levels of poverty, poor health indicators, gender inequality, rampant private healthcare, and corruption are some of the defining features of the region.

Decentralisation has helped the bank's negotiations with the Bangladeshi government in developing a mutually acceptable health programme

Critics argue that the healthcare agenda in Bangladesh is still strongly driven by the bank and are concerned about the sustainability of projects