

Letters

Predictive testing for Huntington Disease

SIR

The recent essay by Jean Adams on the subject of confidentiality and Huntington Disease (HD) (1) highlights the need for further discussion of the technical and ethical issues involved in predictive testing.

The case described is a woman with a family history of HD who has symptoms of HD and who presented herself for diagnosis, insisting that none of her family should be told. Ms Adams argues that the doctor has an obligation to inform the patient's daughters of this diagnosis and its implications, which obligation supersedes his duty of confidentiality (ie to the mother). Furthermore, Ms Adams suggests that the doctor should attempt to persuade the patient to have her blood 'tested for Huntington's chorea'.

Testing of a blood sample to confirm the diagnosis of HD is an inappropriate use of the current technology. DNA analysis using linked markers provides a probability estimate that a person has inherited the gene for HD. It *does not* provide information about the significance of current symptoms (2). The Ethical Issues Policy Statement of the World Federation of Neurology (WFN) and the International Huntington Association (IHA) clearly states:

'The predictive test provides an altered risk of whether someone has or has not inherited the gene, but does not make a current diagnosis of HD' (3).

Furthermore, at the present time there is no method to test a single blood sample for the presence or absence of HD. DNA samples are needed from numerous relatives in order for predictive testing to be informative. No mention is made of this by Ms Adams.

As to the issue of whether the woman

should be persuaded to undergo further testing because of 'how valuable the information could be to her children in planning their families', Ms Adams suggests that the woman will likely consent to testing when so persuaded by her doctor. Ms Adams further suggests that if the patient doesn't consent to disclosure, the doctor should attempt to persuade her 'that her attitude is selfish', an approach which clearly would be coercive. Any consent to testing given under these circumstances could not be a valid consent.

'The decision to undertake the test is the sole choice of the person concerned. No requests from third parties, be they family or otherwise, shall be considered' (4).

Regardless of whether any additional testing is undertaken, Ms Adams argues that the doctor has an obligation to inform the daughters of their risk for HD, irrespective of the patient's wishes in this regard. Ms Adams states that the doctor must tell the patient that 'she cannot bind him to absolute confidentiality in a matter which may so deeply affect the lives of her children'. Powerful arguments can be made regarding the importance of this information for the daughters, but can any of them be sufficient to overrule the patient's own autonomy?

The principle of autonomy requires respect for the individual's right to make an informed decision about an action which may have a profound effect on his or her life. We would agree that the doctor has an obligation to discuss with his patient the issues of further testing and informing family members that they are at risk for HD. However, the doctor's role is to ensure that his patient makes informed choices and he *must not* act directly against the wishes of his patient.

Predictive testing for HD is far more complex than had been anticipated.

Ethical dilemmas associated with this type of testing have been discussed (5). Comprehensive guidelines are needed for this type of testing for HD and for other late onset genetic disorders.

References

- (1) Adams J. Competition in medical ethics: Confidentiality and Huntington's chorea. *Journal of medical ethics* 1990; 16: 196-199.
- (2) Bloch M, Hayden M R. DNA testing in Huntington Disease results in a modification of risk and not diagnosis of disease. *European journal of paediatrics* 1990; 149: 513.
- (3) Ethical issues policy statement on Huntington Disease molecular genetics predictive test. *Journal of medical genetics* 1990; 27: 34-38 (section 5.2.5).
- (4) See reference (3): section 2.
- (5) Huggins M, Bloch M, Kanani S, et al. Ethical and legal dilemmas arising during predictive testing for adult-onset disease: the experience of Huntington Disease. *American journal of human genetics* 1990; 47: 4-12.

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