Journal of medical ethics 1993; **19: 121–122**

Letters

Huntington Disease: Prenatal screening for late onset disease

SIR

In a recent issue of this journal, Stephen G Post (1) presented what he calls 'a set of moral arguments regarding the selective abortion of fetuses on the basis of prenatal screening for late onset genetic diseases only, and for Huntington's Disease (HD) in particular', which represents a very narrow point of view and does not appear to take all the facts into account.

The fact that Huntington Disease (HD) is inherited as a classical autosomal dominant trait with full penetrance and fairly consistent expression is not once mentioned in Post's article. When he speaks of 'selective abortion' for HD and what he calls 'the parental desire to avoid bringing suffering into the world' and 'the ambiguity of desiring "perfect" babies' the impression he gives is that he has overlooked the vital fact that one of the parents is the member of a family in which there is a history of HD.

This means that one parent has either a theoretical high risk (25 or 50 per cent) of having inherited the gene for HD or that the at-risk individual has already taken part in a presymptomatic testing programme for HD and has been given an increased risk (up to 99 per cent certainty) of having inherited the HD gene. In addition, such a prospective parent, by virtue of the fact that he or she comes from a family with a history of HD, has probably had first-hand experience of the devastating effect that HD can have on the immediate family.

Anyone who has been involved with caring for an HD patient is aware that the disease and its associated problems are a tremendous burden on the affected individual, the family involved and the community as a whole.

We know too that HD is not just the passing on of a lethal gene from affected parent to child, but that it has the secondary psychological effects of a frightening and inaccurate store of knowledge combined with a panic-stricken strategy for living. This combination of factors creates a vicious circle of disease, fear, ignorance and further disease. Often it is the unaffected parent that has eventually to carry the brunt of the disease and its accompanying problems. Alcoholism, suicide and divorce are common consequences of HD in these families and it is therefore from this perspective that the prospective parents present themselves for prenatal screening for HD.

The very next article in the same issue of this journal (2) highlights the ethical problems identified and the solutions adopted in preclinical protocols designed to precede the eventual implementation of predictive testing, as well as prenatal diagnosis for HD, which illustrates how much thought has gone into the planning of such genetic prediction. The most important point that this review article (2) makes, is that as a result of the discovery of the first genetic marker for HD in 1983, and the initiation of experimental testing in 1986, presymptomatic testing for HD has left the realm of the hypothetical and is now used in a clinical setting in a number of centres throughout the world.

Stephen Post's article refers to 'selective abortion for HD' and suggests that 'perfectionism' is the sole goal of this choice. Can one honestly justify denial of the option of a choice of termination of pregnancy to a parent who knows that he or she will eventually die from this devastating and debilitating disease and that the next generation will possibly suffer the same fate?

References

(1) Post S G. Huntington's Disease: prenatal screening for late onset disease. *Journal of medical ethics* 1992; 18: 75–78.

(2) Terrenoire G. Huntington's Disease and the ethics of genetic prediction. *Journal of medical ethics* 1992; 18: 79–85.

JACQUIE GREENBERG PhD
Department of Human Genetics
UCT Medical School
University of Cape Town
Observatory, 7925
South Africa.

Patient satisfaction: an imperfect measurement of quality medicine

SIR

Much current medical, paramedical and particularly political talk is that so far as quality in the NHS is concerned it is the arbitraments of patients which are its sovereign measure. The Patient's Charter (1), for example, has consumerism concentratedly flowing through its bloodstream; the GPs' new contract (2) instructs them to carry out consumer surveys to measure patient satisfaction. Two beguilingly simple notions underlining the premise need examination: 1) That if the patient is satisfied then decent quality medicine has been enacted (and so the NHS has done well); 2) That if the patient is unsatisfied then the doctor and the NHS are at fault.

There is a problem with using a consumerism mentality in medicine. What patients earnestly believe they need – in the way of medication, investigation or referral – may not, by