Introduction

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Genetic testing in children

The last two decades have seen a substantial increase in the number and type of genetic tests that can predict whether or not an individual has an inherited predisposition to cancer and is likely to develop it in the future. The issue of if and when it is appropriate to test children for later onset conditions (including cancer predispositions) has been considered by many. Several different national and international professional guidelines adopt a cautionary, if not prohibitory, approach to this issue. This issue of the Journal brings together 14 papers which examine the topic of childhood genetic testing from different angles. Although many focus on the issue from a cancer perspective, there is also a more general discussion of the ethical and legal issues involved. For example, Ainsley Newson and Samantha Leonard consider the ethical issues raised by pre-adoption predictive genetic testing for cancer. They argue that, under a principle of consistency, such testing should be discouraged if the same test would not be offered for a child who is with his/her biological family. Robert Wheeler explores the legal aspects of a UK case in which a court order led to a child being tested for a cancer predisposition prior to adoption. Roy Gilbar compares different countries' legal perspectives on Consent, Communication of Information and Confidentiality. Tara Clancy reviews

the ethical issues in prenatal diagnosis and preimplantation genetic diagnosis for later onset inherited cancer predispositions. Gareth Evans and colleagues and Gill Crawford provide case reports illustrating some of the difficulties that arise in clinical practice. Michael Parker gives an overview of the range of cases involving predictive genetic testing in childhood that have been discussed at Genethics Club (www.genethicsclub.org) over the past 8 years. Pascal Borry and colleagues look at commercial companies' attitudes to testing of minors for direct to consumer testing. Suzanne O'Neill explores primary care opinions about BRCA1/2 testing in minors; Beth Peshkin has developed a decision support intervention for mothers undergoing BRCA1/2 testing to facilitate communication with their daughters. Jonathan Montgomery and Anneke Lucassen summarise the state of play with professional guidance around this topic in the UK. Angus Clarke argues that we are right to have guidelines urging caution for such testing; Angela Fenwick questions whether guidelines might lead to 'tick box behaviour', and instead supports the use of case by case assessments.

It is interesting that whilst there are nearly 30 national and international guidelines that state that genetic testing in childhood for adult onset conditions should be deferred (so that children can decide for themselves at a future date), this issue continues to arise in clinical practice. But guidance does not proscribe what should be done in all cases. Rather than telling parents that guidelines prohibit testing of their child, engaging them in a discussion about the pros and cons of testing is more likely to result in a mutually satisfactory outcome.

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