Testing children for adult onset conditions: the importance of contextual clinical judgement

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Genetic testing—either to diagnose a condition or predict its chance of occurring in the future—has become more widespread in medical practice. Rapid advances in technology mean that quick and affordable results can be obtained in an increasing range of situations which can help the clinician determine, for example, treatments, surveillance or preventive options. Whether and when such tests should be done *before* the potential onset of a condition, and in those too young to yet decide for themselves whether they want this information, remains a debated issue.

On the one hand, parents have a legitimate interest in discovering what the future might hold for their children. Helping children and their parents to come to terms with a likely genetic condition in the future at an early stage and gear their lives accordingly could be seen as an argument in favour of testing. On the other, if that future will not be realised until the children have grown into adults, then why not wait until the children are old enough to decide for themselves whether *or not* they want to know this information? Providing parents with a crystal ball about their children as adults may not be something that health professionals see as their role, or indeed be thanked for providing by the children as they grow older. Parental requests for such testing of a young child, who cannot be involved in the decision, for a condition that will not affect him or her during childhood, or perhaps even early adulthood, need to be explored with parents since neither argument is definitive and likely to be applicable in all circumstances.

If we are agreed that protecting the (best) interests of the child is at stake, then the debate is not so much whether to test or not, but how to make any decisions around testing as considered as possible, and how and when to involve the future-at-risk adult in the process and, if testing is to be done, what the best timing of such testing might be. Parents are familiar with investigations of their children that provide contemporaneous information about health or development, but dealing with predictive testing that sheds light on possible/likely (ill) health many years in the future is less common in healthcare and so a first step is to ensure that parents making such requests have thought about the differences and are aware of some of the ethical arguments. Moreover, discussions about testing a baby will be different from those of a 15-year-old, and parental views about the independence of their children and their role in any decision-making process will also be age-dependent. We view the families who enquire about 'predictive testing in minors for late onset conditions' as a heterogeneous group: decisions about if and when to test will depend on the individual circumstances including the nature of the condition that is to be predicted, the likely age of onset, the certainty of the prediction and the means to prevent, treat or ameliorate it.

In this context, we find the paper by Mand *et al*[1] somewhat perplexing. The authors discuss 'diametrically opposed views' and 'controversy', yet a 'prevailing inertia' and an 'overall lack of systematic work'. These conclusions imply that there is some 'correct answer' yet to be found: possibly by overcoming the inertia, making better efforts or by gathering enough empirical evidence about predictive genetic testing in minors for late onset conditions. The abortion debate rages on as strongly as it did 30 years ago; does this mean there has been a lack of systematic work or empirical evidence?

By describing the 'battlefield' the authors hope to provide a 'new framework for understanding the debate', yet we are left unclear as to what this new framework is or how the description of the 'impasse' aids understanding. The paper adopts a quantitative approach in that it makes a tally of the different arguments presented in a range of academic papers, but this ignores whether an argument is used in favour of testing or against and does not provide any context to the arguments in the literature. Any one article might therefore present clear arguments against previous stances, but because these are simply listed as a tally, the authors conclude that there is an impasse.

Interestingly, Mand *et al*[1] state that formal guidelines do 'not provide a framework or criteria to guide a choice process', but a review of guidelines or their stances and arguments has been specifically excluded from this article and so it is not clear how this conclusion is arrived at. In the UK, the British Society of Human Genetics produced guidelines in 2010 that outlined both a framework and criteria for testing.[2] Other reports in the literature that discuss the complexities of individual cases and advocate support for parental decision-making rather than a 'for' or 'against' stance[3 4] are also not reviewed. Indeed, the suggested solution of 'guidelines that allow clinicians to…make…clinical and moral decisions based on their judgment in individual cases' is dismissed as a less good option to the proposed gathering of robust empirical evidence to see whether testing is right or wrong.

It is unlikely that this debate can have a straightforward answer nor is the gathering of empirical evidence perhaps as useful in determining what is right or wrong as the authors claim. What the correct decision is for one family and one set of circumstances will be the wrong one for the next, precisely because the context is so important. Empirical work could, however, help us to understand and explore different perspectives/contexts or reveal the consequences of different actions on different family members. For example, helpful evidence from certain types of genetic testing suggests that initial requests for genetic testing may not be sustained after consideration of the issues involved.[5] Conversely, those who think there is no point to genetic testing may change their mind if they learn that treatments or interventions may be effective in modifying their inheritance. What these observations tell us is that initial expectations of genetic tests may be inaccurate or open to discussion.

While there is no doubt that the arguments for and against such genetic testing

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have been well rehearsed in the research literature, this does not necessarily need to result in a 'stalemate' or 'inertia' in the clinic where such requests are dealt with. Recent guidelines[2] recommend the consultation should help parents to consider the issues at stake and arrive at a considered decision or the 'most right' decision in the particular family context. This may mean that sometimes there is disagreement about what is in the best interest of children, both before and after they can make decisions for themselves, but this is the case in many areas of medicine. Searching for *the* right answer to the question of predictive genetic testing during childhood for adult conditions is unlikely to be successful.

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REFERENCES

1. **Mand C,** Gillam L, Delatycki MB, *et al*. Predictive genetic testing in minors for late onset conditions: a chronological and analytic review of the ethical arguments. *J Med Ethics*. Published Online First: 8 March 2012. doi:10.1136/medethics-2011-100055
2. *British Society of Human Genetics; Guidance on the genetic testing of children. An Update of the 1994 UK Clinical Genetic Society guidance*. http://www.bshg.org.uk/GTOC_2010_BSHG.pdf (accessed 30 Apr 2012).
3. **Newson A.** Clinical Ethics Committee Case 8: should we carry out a predictive genetic test in our young patient? *Clin Ethics* 2009;**4**:169—72.
4. **Crawford G,** Lucassen A. Predictive genetic testing in a young child: a case report. *Fam Cancer* 2010;**9**:61—4.
5. **Harper P,** Lim C, David C, *et al*. Ten years of presymptomatic testing for Huntington's disease: the experience of the UK Huntington's Disease Prediction Consortium. *J Med Genet* 2000;**37**:567—71.

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