Biotechnology and general practice. 2. Beyond the technology — social and ethical problems

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Introduction

LAST month's article on biotechnology reviewed recombinant DNA techniques, monoclonal antibodies and genetic probes and examined some of the clinical implications that these hold for general practice. In this article we look initially at the problems these technical innovations pose for postgraduate education and then move on to their implications for screening in general practice. The final part of the article explores some of the wider issues raised by genetic engineering that have been briefly touched on in the first paper. We believe that such a perspective is vital if we are to retain control of this technology.

Postgraduate education

The next decade will see a rapid increase in our understanding of physiology and pathology. New tests and pharmaceuticals will follow soon after. The wide range of pathology presented to general practitioners means that the issues will be particularly relevant to primary care. How are we going to cope with such a large amount of new knowledge? The Royal College of General Practitioners' Quality Initiative is an admirable attempt to overcome the organizational difficulties of applying well-known principles. The new drugs, tests and screening programmes that will appear in the next decade as a direct consequence of the revolution in molecular biology underline just how vital are such efforts at improving general practice.

Screening

Biotechnology will affect screening for disease in several ways. First, there is the potential for using DNA probes to screen for an increasing number of genetic predispositions. Currently this technique is limited to serious conditions such as muscular dystrophy and is mostly used during early pregnancy. It is likely, however, that the number of diseases to which screening can be applied will increase to include some of the common major diseases. Secondly, monoclonal antibodies are being used to develop a number of tests to detect particular diseases at a very early stage. Although not yet of proven value this approach is likely to lead to new screening tests, which will broaden the opportunities for primary and secondary prevention.

Such advances intensify the ethical problems raised by screening. Our attitude to screening for asymptomatic disease is exemplified by the opportunistic approach to hypertension screening. 'By the way while you're here ... ', we say and strap on a sphygmomanometer cuff. Such an approach is unethical to the extent that it denies people an informed chance to refuse the test. By contrast the current practice in testing for alpha-fetoprotein recognizes that pregnant women may not wish to know if their child is abnormal and hence they must understand the implications of the test before it is performed. A generalized test for carcinoma or the ability to tell someone that they have inherited an increased risk of developing ischaemic heart disease generates information that people may understandably not wish to know.

Screening fetuses antenatally also raises the ethical issue of deciding which conditions are serious enough to justify termination of pregnancy. The ethical problems of antenatal diagnosis have so far been relatively peripheral: the severity of Down's syndrome combined with society's moral pragmatism has made it fairly easy to establish amniocentesis as reasonable practice for individuals at high risk. This consensus is likely to become relatively strained as more conditions become diagnosable during the first trimester. Would it be reasonable for instance to terminate a pregnancy where the fetus has a high risk of developing type I diabetes? Weighing up the medical, parental and legal factors in reaching these decisions is not going to be easy.[1]

The ways in which we perform screening in general practice must therefore change so that we use the increasing number of tests effectively and take greater account of ethical issues. The amount of time that general practitioners will choose to spend on screening, the organizational difficulties that will be intensified and the ever greater divergence in quality of care between different general practitioners are all problems that we will have to face.

Wider issues

In many ways biotechnology is similar to previous advances in technology: it creates new ways to control and manipulate the natural world and these in turn generate their own problems. However, genetic engineering raises issues other than simply the wise use of technology. If the tangible gains of biotechnology are often spectacular the wider social and political effects are just as great. These secondary effects are necessarily more speculative and philosophical than the medical advances but they are intrinsic to those advances. The cloning and production of human growth hormone, for example, is of clear benefit to those children with definite deficiency syndromes (especially in view of the recent linking of Alzheimer's disease to cadaver-derived human growth hormone). Paediatricians in the USA, however, are now finding themselves under pressure from parents with short, but not growth hormone-deficient, children, who want their child to be of 'normal' height. This is combined with pressure from the manufacturing companies who invested in producing recombinant human growth hormone and are clearly interested in expanding the market for their product.[2,3] Both the clear therapeutic advance and the ambiguous secondary use are inherent in the same technology.

A new reductionism

Currently medicine sees the cause of disease mainly in terms of disordered cells. Although the wider aspects of environment and personality are increasingly taken into account, the apparent success of technically complex medicine tends to undermine this.

Biotechnology offers another level to this process of reductionism. The real problem is now seen to lie within DNA itself: cellular, hormonal and organ pathology are merely the consequences of a disordered 'master programme'.

This approach is going to produce many clinical and therapeutic breakthroughs. There are dangers however. First, the seduction of achieving an apparently complete understanding may lead to a new 'silver bullet' approach. This reinforces the idea that many medical conditions can be solved by technical means aimed at correcting the underlying pathological fault without regard to the wider social and environmental causes. For example, it might be possible to determine which smokers have a genetic predisposition to lung cancer and concentrate preventive measures on them. Of course, smokers with negative tests would then continue to smoke, happy in the knowledge that — as they always knew — they were not going to get cancer. If we regard the effects of smoking as the individual's own problem, social solutions (using taxation, for example) become more difficult to apply. With each technological advance the importance of genetic causes and solutions may become emphasized above other more nebulous but equally important factors. Put another way, it may become harder to see the psychological, emotional and social components of illness at a time when the physical causes and solutions are proving particularly successful.

Reductionism has many forms, all of which seek to reduce a complex set of causes to one single level. Genetic reductionism sees the organism as reducible in essence to its genes and their activity. Like most forms of reductionism, this approach is plausible but simplistic. It may be a useful way to generate new knowledge, but there is the constant danger that a methodological tactic may be taken for the whole truth.[4,5]

Controlling our own genes

The ability to manipulate DNA opens up a number of new conceptual, diagnostic and therapeutic possibilities. A growing concern about reductionism is in part a response to the emergence of these possibilities. But there is another fundamental issue to be considered and this is the question of choice. It is easy to say that increased choice in medicine is a good thing. Yet it is still important to ask how particular choices are made, and according to what criteria.

The ability to predetermine the sex of a fetus illustrates the complexity of the problem. Most people would be against such a development, even though it increases the degree of choice and control. However, the veterinary applications and the desire to eliminate sex-linked disease in humans are some of the commercial reasons that have already led to intense research on predetermining fetal sex.

A second problem is that even though many people would say that they were uninterested in such a technique, the very existence of the choice would be an inescapable issue for everyone having children. These advances often alter the way in which we see our biological nature; events that previously were thought of as being completely beyond our control would become subject to choice.

Finally, the ability to choose whether to have a girl or a boy would lead to some changes in the numerical balance between the sexes. The evidence is that the number of first-born women would drop, thus strengthening the culturally defined barriers against women. Individual choice, which our society values greatly, could reinforce the cultural stereotypes that already restrict women's freedom.

In the fairly near future it is possible that we will be able to significantly affect the kind of children that are born. The last 15 years have seen the growth of the technology of 'fertility control'; will the next 15 years be marked by the growing technology of 'quality control' for fetuses?[6] Enthusiasm for eugenics can take horrific forms as in, for example, the sterilization programmes in many countries in the 1920s. But such vigorous measures to interfere genetically with the population rose to pre-eminence because they seemed 'common sense' at the time and were supported quite widely within the medical profession. The new genetic technology greatly extends the scope of eugenics. The norms that we are evolving now are potentially just as fallible as they were 60 years ago. It will require the greatest caution, constant scrutiny and a sense of political context if we are to remember the lessons of history.[7]

Conclusion

In these articles we have tried to give an idea of what biotechnology will mean for us as doctors and as citizens. We have been far from exhaustive: oncology, neurophysiology, the understanding of the immune system and autoimmune disease and the mechanisms of embryonic development are some of the other areas that are changing rapidly.

There are two common responses when contemplating such large, but as yet undefined, developments. Some of us become fired with enthusiasm for the new technical utopia that awaits us. Others react with 'apparent horror at the incredible scenes unfolding before our eyes [but] deep in the heart [often] relish the excitement and perversity of it all'.[8] Most of us of course merely oscillate between these two poles of hope and foreboding, transfixed and confused by the sense of helplessness induced when such technological virtuosity is being used by others to shape the world.

What can be done to ensure that we end up in control of this new technology rather than dominated by it? First, it is important that the public knows about the advances and has reflected on the problems involved. With regard to biotechnology general practitioners are, by and large, as ignorant of what is in store as their patients. This is actually quite a good starting point since we are likely to experience the same feelings of insecurity and confusion as our patients. We, however, will need to learn what the advances have to offer and, by combining both our professional outlook and our relatively lay view of the technologies, create a discerning scepticism so that our patients may receive high quality care. Bodies such as the RCGP and the College of Health could play a key guiding role over the next few years by sponsoring working parties or meetings to discuss advances critically and define a response to them. These events will, in our view, only be worthwhile if they secure significant lay participation.

The dilemmas concerning screening can perhaps be tackled by emphasizing approaches to preventive care that are patient-centred. We often imply in our preventive care that we know best. This attitude may become less acceptable as the number and variety of screening tests we can offer grows. Even where a test is of proven worth it may still be that the patient would not, with full knowledge, wish to be screened. Knowing that one has a three-fold increased chance of developing carcinoma or that one carries the gene for cystic fibrosis may be a mixed blessing. Setting out the risks and benefits of such tests to patients must become just as much a part of preventive medicine as proving that the screening programme itself does indeed affect mortality or morbidity.

Genetic engineering offers opportunities for both good and ill. General practice is likely to be one of the arenas in which

the ethical and practical dilemmas are battled out. Family medicine may be able to form one defence for our patients against the excesses that seem inevitable when any powerful new technology is being developed. But we also need to be aware of the important advances that are likely to become available to our patients and to practice a medicine that takes advantage of the best that biotechnology has to offer. Such discriminating knowledge, skills and attitudes do not appear overnight: we need to be researching, planning and educating for them now.

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Chronic otitis media

Does chronic otitis media with effusion during early life have lasting otologic, audiologic, or developmental consequences? The authors of this study evaluated 24 closely matched pairs of children with repaired palatal clefts whose treatment had been equivalent except with regard to persistent otitis media during early life. One group had undergone early (mean age, 3.0 months) myringotomy with placement of tympanostomy tubes, followed by assiduous monitoring and an aggressive treatment programme to maintain ventilation in the middle ear. The other group had undergone initial myringotomy later (mean age, 30.8 months) or not at all (two subjects) and presumably had had continuous middle-ear effusion throughout most or all of the first few years of life.

Eardrum scarring was equal in both groups. Hearing acuity and consonant articulation were impaired in both groups, but hearing acuity was less impaired ($P = 0.05$ to 0.10) and consonant articulation significantly less impaired ($P = 0.03$) in the group undergoing early myringotomy. Mean verbal, performance, and full-scale IQs and scores on psychosocial indexes were normal in both groups and did not differ significantly between the groups.

These findings support the hypothesis that early, long-standing otitis media may result in impairment of hearing and of speech, but they do not support the hypothesis that cognitive, language, and psychosocial development are adversely affected.

Source: Hubbard TW, Paradise JL, McWilliams BJ, *et al.* Consequences of unremitting middle-ear disease in early life. Otological, audiological, and developmental findings in children with cleft palate. *N Engl J Med* 1985; **312:** 1529-1534.