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Lifelines: Human Genetics

It is less than 50 years since the double-helical structure of DNA was famously elucidated. In this short space of time huge advances have been made in molecular genetic techniques, and equally huge advances in our knowledge and understanding of human genetics. And all the while the popular press would have us believe this heralds a Frankenstein future of automatons and super-beings, or that it may be the salvation of humankind.

The Human Genome Project has already published a draft version of the genetic information contained in the entire human genome (200 telephone directories-worth of information). A growing number of genes have been identified which are directly responsible for inherited diseases like cystic fibrosis, Huntington's disease and Duchenne muscular dystrophy. The identification of disease-causing genes has led to the development of genetic tests, and the possibility of gene therapy. An additional number of genes have been suggested as contributing to a variety of conditions from diabetes and heart disease to homosexuality and shyness. The birth of Dolly the sheep opened up the possibility of human reproductive cloning, and the use of human embryonic stem cells for medical purposes. Further into the future lies the hopes or fears of individual genetic printouts given at birth, genetic enhancement technology, germ-line genetic therapy (affecting the genetic make-up of future generations) and eugenics.

For the Christian these tremendous developments, and this amazing growth of information, raise a trinity of interrelated and interconnected issues: those of ethical, pastoral and theological natures. How should we best use the knowledge and techniques we have discovered? What will it mean to work towards justice and wholeness in human genetics? Are there skills we should never use, boundaries we should never cross? What pastoral support can one offer to individuals affected by genetic technology or knowledge? How do these genetic advances affect our understanding of the place and role of humanity in creation? What does it mean to be human, to be healthy, to be made in the image of God, to be free, to possess a soul? Carefully considered and presented responses from a Christian perspective are needed to guard against the hyped-up fears or hopes shrieked through the tabloid headlines.

Towards an ethical response

Around thirty years ago, the possibility of human genetic manipulation prompted Paul Ramsey and Joseph Fletcher to published their considered ethical responses, from deontological and utilitarian viewpoints respectively.¹ For Ramsey, certain God-given limits to human life should not be crossed no matter what the consequences, such as separating the unitive and procreative goods of human sexuality. Whilst for Fletcher, to be human means to take responsibility and to use genetic technology wherever possible in to assert control over human reproduction. Fletcher would have us use our God-given skills and knowledge to control the outcome of our own future. These works have become classics in their field. Sadly, as developments and advances have been made in scientific circles, there has not been a parallel advance in Christian ethics or theology. I am unaware of any recently published books offering a Christian ethical response to the issues raised by genetic technology, which are written by a single author.² A number of books have been written in the form of a collection of essays, these have the advantage of being able to offer a variety of perspectives and conclusions, but the disadvantage of being unable to explore a particular viewpoint in great depth.

On the specific issue of human reproductive cloning, triggered by the existence of Dolly the sheep, *Human Cloning: Religious Responses* is one such example.³ A common thread through many of the essays is the recognition that genetic technologies need to be used within limitations. Limitations are necessary because of the finiteness and the fallibility of humankind.⁴ Genetic technologies are powerful and temptations to misuse them will also be powerful⁵, such misuse could be seen in reproductive cloning in terms of the commodification of babies⁶, or the use of technology to assert power over other human beings⁷. A recognition of the fallibility and finiteness of humanity also reminds us of the reality that we are not perfect, perfection cannot be sought through cloning (or any other genetic technology) but only through relationship with God (being 'cloned' into the body of Christ).⁸ Despite this common thread, a variety of conclusions are made as to the ethics of human reproductive cloning, these reflecting the theological persuasion of the contributors. A feminist theologian would allow lesbian couples to use cloning techniques in order to become parents, on the grounds of equal rights.⁹ A Roman Catholic would allow no reproductive cloning, on the grounds (among others) that embryos are fully human and should not be subject to experimentation or destruction.¹⁰ Meanwhile, a Lutheran sees no reason to ban human reproductive cloning so long as the resultant children are treated with dignity.

1 Paul Ramsey, *Fabricated Man: The Ethics of Genetic Control*, Yale University Press, New Haven 1970.

Joseph Fletcher, *The Ethics of Genetic Control: Ending the Reproductive Roulette*, Anchor Books, New York 1974.

2 I will be very happy to be contradicted on this point.

3 Ronald Cole-Turner, ed, Westminster John Knox Press, Louisville 1997.

4 Donald Bruce, p 6.

5 R. Albert Mohler, Jr., p 102.

6 Ted Peters p 21.

7 David Byers p 76.

8 Stanley Hauerwas and Joel Shuman p 64. Or should that be the old-fashioned technology of grafting?

9 Karen Lebacqz, p 53.

10 David Byers, p 70.

A compilation book, which covers most areas of genetic technology, is *Genetic Ethics: Do the Ends Justify the Genes?*.¹¹ Articles on the Human Genome Project, and genetic-testing, -patenting, -counselling, and -intervention, describe issues, which are raised by these advances and theological responses to them. Additional articles provide historical, sociological, theological and pastoral contexts to the ethical questions. Theologically the book has more coherence as most contributions are from an evangelical Protestant perspective.

One of the phrases that are often used in connection with any genetic intervention is that of people 'playing God' – generally in the sense that people should not do so. But what exactly does 'playing God' mean? Allen Verhey describes the way in which the phrase is often used to mean that human powers are awesome, or that the consequences of 'interfering with nature' are worrying, or that humans should not trespass into those areas of knowledge and power left to some 'god of the gaps'. On other occasions humanity is encouraged to 'play God' in the sense of taking a 'messianic' responsibility for the state of humanity because of the apparent absence of God. None of these understandings of the phrase are appropriate from the Christian perspective. The Christian understanding of God as the One who created, sustains and will fulfil all that is, who always has been and always will be involved with his creation, leaves no room for a 'god of the gaps' nor for human beings to take on a 'messianic' role. Recognition of the fallibility and fallen-ness of humanity equally makes a mockery of such a concept. Yet we still have a God-given responsibility to care for God's world and his people, and to use our skills and knowledge well. Verhey suggests we should 'play God' in the sense of imitating or following God, 'to follow in God's way like a child "playing" a parent'.¹² In this sense Verhey would have us think particularly about 'playing God' as creator, healer and the one who takes the side of the poor.

Neither of these books offers much in the way of specific guidelines for the use of any genetic technology, and often the conclusions of contributors contradict each other. They are useful in helping one to recognize the ethical issues raised by genetic advances, but not in helping one to answer the questions raised by these issues. At least Ramsey and Fletcher were clear in what they thought should or should not be done.

Towards a pastoral response

It is not unusual for Christian people, both lay and ordained, to be sought by those outside or on the fringes of (as well as those within) the faith, for support, advice and encouragement during crisis points in their lives. How are Christians to offer pastoral support to the increasing number of people caught up in situations involving genetic technology? Our difficulties in offering support are often twofold, in that we do not understand the technology involved, and we do not know how our understanding of God applies to the situation. In response to these difficulties the Episcopal Diocese of Washington has produced a study book on the issues

11 John Kilner, Rebecca Pentz and Frank Young, eds, Paternoster Press, Carlisle 1997.

12 p 68.

relating to genetic testing.¹³ The first two chapters offer a basic grounding in the technology of genetic testing and in the theology of the Anglican tradition. In the light of these chapters, issues relating to the testing of foetuses, newborn babies, children and adults are considered along with decisions relating to conception.

Such a short book has no opportunity to go into detailed theological discussions, but it does illustrate the ways in which the basic tenets of our Christian faith impinge on such areas. A short section, for example, discusses why genetic mutations occur and how this fits in with our understanding of a God of love whose creation is good. It is not a case of God wilfully inflicting disease on people, or of him having lost control of his creation. Rather, 'God established the parameters of the way the world unfolds and also allowed chance to play a role in its development'.¹⁴ Chance mutations are vital for the evolution and development of living things, allowing them to survive in changing environments, but these chance mutations can also cause detrimental effects.

Each chapter has a very helpful list of questions, which could usefully be asked of a medical practitioner or genetic counsellor in order to facilitate a more informed decision. Case studies with key questions for consideration are also available to help work through the implications of decisions. At no point is the book prescriptive, but rather often both sides of an argument are presented clearly (for example over decisions relating to the abortion of a foetus with a fatal condition). All decisions are left to the individual in the light of 'life experiences and deeply felt emotions, but also your prayerful consideration of Scripture, the Christian moral tradition, and your God-given power of reason'.¹⁵ As an American publication, the book has the disadvantage of referring to liturgical material and Church resolutions, a legal system and health service, which are different to our own – yet it is still the best practical book which I have come across on the subject. It can be used both to inform pastors, and to pass on to those confronting difficult choices raised by genetic technology.

Towards a theological response

The ethical and the pastoral responses of Christians to genetic technology should be firmly grounded on theology. Advances in genetics also inform and challenge our theological understanding of what it is to be human. It is ironic then, that in the last twenty years, there has been little theological study which either reflects our growing genetic understanding, or which gives us a firmer basis on which to build our ethical and pastoral thinking. In a critical review of the religious responses so far, Audrey Chapman argues that there is a great need for systematic and serious works of theological anthropology as well as theology, which can inform and direct ethical responses.¹⁶ This need can be illustrated very well by considering the theological concept of *imago Dei*.

13 The Committee on Medical Ethics, *Wrestling with the Future: Our Genes and Our Choices*, Morehouse Publishing, Harrisburg 1998. 14 p 41.

15 p 98.
16 *Unprecedented Choices: Religious Ethics at the Frontiers of Genetic Science*, Fortress Press, Minneapolis 1999.

The understanding that human beings are made in the image of God is almost invariably invoked in theological and ethical discussions regarding human genetic intervention. But what exactly do we mean by this, and what implications does it carry? Within the two publications referred to in the first section, the image of God is variously described as meaning: knowing the difference between right and wrong, good and evil, being capable of consciously changing the world, being creative, being able to communicate, reason and exercise dominion, having the capacity for knowledge, righteousness and holiness. Similarly, the implications of being made in God's image are variously assumed to be that: a recognition of the sanctity and dignity of human life is required, humans are worthy of protection, love and respect, all humans are equal, humans should be treated as an end rather than a means. Often the link between the *meaning* of being made in God's image and the *implications* of this, which are given, are neither obvious nor logical. How can we continue to use this theological concept so freely without truly knowing what it means? My personal view (influenced by Barth and Ramsey) is that we do not so much 'bear' God's image as 'reflect' it – and this only through our relationship with God. This not only ties in with Verhey's suggestion that we should 'play God' in the sense of imitating God (how can we imitate him without knowing him and being empowered by him?), but also has huge implications for the genetically disabled. If being made in the image of God has something to do with a capacity for knowledge or creativity, reason or communication, then what does this mean for those people who through genetic disability lack that capacity? The implication would seem to be that these lives are not equal, demanding of worth, sanctity or dignity. However, if God's image is reflected in us through our relationship with him, then his reflection can be seen in the disabled as much (if not more so – because of their greater ability to trust) as any other person.¹⁷

Another theological area, which needs considerable study, is that of what it means to be a human being who is normal, healthy and/or whole, and which of these labels is actually appropriate. This matter will have obvious implications for the extent to which it is considered right to use genetic testing, selection, therapy, and enhancement. Gerald McKenny criticizes the modern expectation that technological medicine should be used to remove human suffering and to increase our lifestyle choices. This expectation he calls the 'Baconian project', and he sees it as involving an unquestioning commitment to the technological control of the body in order to eliminate 'misery and necessity'.¹⁸ McKenny suggests we need to recover an understanding of the moral significance of the body, and that 'the pursuit of health in the context of the pursuit of a good life within the limits set by necessity' is far more appropriate than attempting to overcome our human subjection to natural necessity.¹⁹ Limitations, ageing and death are realities of human life, realities of who we are as created creatures. The pursuit of wholeness is therefore far more appropriate than the pursuit of perfect health, and is

17 Audrey Elkington, *A theological consideration of ethical issues raised by human genetic manipulation, with particular reference to gene therapy*, MA thesis, Durham 1999.

18 p 19.

19 p 15.

something, which depends more on a relationship with the Creator than the use of genetic technology to its limits. I suspect this is what McKenny means by the 'pursuit of health in the context of the pursuit of a good life within the limits set by necessity'. However, humans still have the responsibility of using medicine/genetic technology wisely, whilst not striving to relieve all suffering or offer all possible choices. Sadly McKenny does no more than introduce the phrase 'the moral significance of the body', he does not unpack its meaning theologically, nor does he indicate what this would mean in terms of deciding what suffering it is appropriate to eliminate, or what choices it is appropriate to make.

Conclusion

The field of human genetics is vast, involving so many different technologies, offering so many possibilities. The field of human genetics is also moving at great speed, each day new genes are discovered, new sequences published, new therapies suggested. Basic themes of Christian theology need to be re-examined and re-applied in the face of this new information and new technology, rather than simply responding in a superficial way to each new advance as it happens. Audrey Chapman has pointed this out very powerfully. Gerald McKenny has mooted a new way of approaching bioethics. Elsewhere I have suggested that viewing the tragedy and the hope of human genetics within the context of the tragedy and the hope of the Christian story is one way forward.²⁰ Far more detailed and systematic work is still needed. As Ronald Cole-Turner has suggested: 'Our theology needs to be as sophisticated as the technology it addresses'.

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²⁰ MA thesis.