

Gene Technology and Ethics: New Wine in Old Wineskins?

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Introduction

Gene technology is presenting us with ethical dilemmas that are not quite like anything that we have had to consider before. We have shattered some of the physical and biological constraints on our actions, and now need to find new ways of both being and acting in the world. Our traditional ethics can provide us with guidance in some areas (particularly as it relates to applications of gene technology to medicine), but our new-found ability to manipulate life raises some deep challenges to the frameworks within which we construct our ethics. We could reduce ethics to utilitarian or pragmatic calculations of risks and benefits, and within these terms there are important considerations of who benefits and what risks we factor in. But I will argue that gene technology pushes us to examine the wider frameworks within which we construct our ethics – what does it mean to be human? how do we create meaning and value? against what ‘horizon’ do we understand the choices that we can now make? I argue that gene technology is requiring that we construct a new ethics, building on that which is recognised as of central importance to us, but taking into account the new possibilities that are now with us. We cannot put new wine into old wineskins – the results could be disastrous.

New capabilities

Copernicus inaugurated dramatic change in world view when he recognised that the world was not the centre of the universe, but rather that the earth moved around the sun. This discovery, obvious and routine information now, nevertheless signalled the beginning of a social revolution. Such a de-centring of the world destabilised powerful social institutions such as the church. When the physical world was seen differently, so was the social world. Social institutions were based in a particular world view, and when that changed so did many other things.

Gene technology, I argue, brings us to another significant point in history when the capabilities of science have the potential to precipitate social change of the same magnitude as the Copernican revolution. On one level we have merely developed new tools, new technology, new cultural artefacts – new ‘means’ for continuing to do what humans have always sought to do, to resist disease and death, to feed ourselves better and more easily. But on another level we now have the capability to do much more – we are developing the potential to change evolutionary paths of other organisms, to ignore physical barriers to breeding, to harness for human gain myriad biological processes, to be in charge of our own evolution (which may yet take the form of extinction), and have private ‘ownership’ of biological characteristics and even organisms.

Gene technology has potential for harm – physical, psychological and social. It also has enormous potential for good – for treatment and prevention of disease, for faster breeding of superior crops and animals for food, for rapid production of drugs. We have always sought to do such things, but now we are developing a power that was unimaginable little more than a generation ago. It is the stuff of magic! Transformations that alchemists dreamed of! But the power, the capability to do these things is now with us. We are confronted with a new edge to the ethical question that echoes through the ages: ‘How shall we live in a world like this?’ How do we, as individuals, as scientists, as communities, live with the responsibilities that come with the enormous power and potential that is gene technology?

The contribution of traditional medical and scientific ethics

Traditional ethics can go some way to helping us to deal with some of the ethical choices we must make about how to live with and use gene technology. Within medicine and science

there are clear articulations of values that are important. These are based in the fundamental ethical intuition of the worth and dignity of the human person, now, in Western culture, firmly linked to the notion of autonomy. (This notion is, of course, expressed in various ways in different cultures and times.) Other principles of beneficence, non-maleficence, justice and care articulate a framework within which health care providers seek to discern what makes for ethical practice. Health care professionals recognise that people have the right to make their own choices about what is the best decision for them, what treatments they will or will not accept, what balance of risks and benefits make sense in their own lives. This is the basis for the emphasis on informed consent in medical care. The practice of health care also recognises that the responsibility of the health professional is to do good for the patient (beneficence) and (from the Hippocratic oath) above all do no harm (non-maleficence). In these days of commercialisation of health care, expanding possibilities for treatment and escalating costs, the value of justice (most frequently discussed with reference to just distribution of resources) and care of the vulnerable are also important.

Science also identifies some behaviours that are important for ethical work – honesty in reporting results, openness of information, no cheating or plagiarism, integrity in application of research methods, appropriate use of animals. These values reflect a fundamental value in science – that of the value of knowledge. Knowledge is often seen as having intrinsic worth and value, in and of itself.

Such values are important, and useful as we explore the ethics that must underpin the development of new technologies. They can help us think through many of the novel situations in which we find ourselves, and to identify areas where processes, regu-

lation or legislation are necessary, for example to protect human dignity and autonomy.

For instance, gene technology has introduced the possibilities of genetic testing for some conditions. When and *how* these tests are offered needs to be done with due care if it is to be ethical. People being tested need to give fully informed consent for the procedure for taking a tissue sample, and for what tests are to be done, who will see the information, what else will be done with the body sample. The implication of results (e.g. for health care insurance and for the family), and subsequent uses of the tissue sample (e.g. in research) need to be known to people prior to their making a decision about whether or not to proceed. To do otherwise is to fail to show respect for a person's autonomy.

Limitations of traditional medical and scientific ethics

But the limitations of these approaches will be apparent to those who work in research laboratories or private biotechnology enterprises, those who negotiate the boundaries between medical and business ethics, or those who look at international trade issues. Science and research can no longer pretend that it is a pure enterprise in the pursuit of disinterested knowledge. Such a belief may have been possible in the early days of science, when many scientists were people of independent means. But these days the research agenda is driven by priorities of funding bodies, the demands of government, of business, and of trade. The values here are not pursuit of disinterested knowledge, nor necessarily the benefit of all humanity.

Gene technology has moved well outside ethical decisions that can be contained within frameworks of medicine or science. As a community we are needing to identify values we will affirm and protect as different social practices and institutions come into conversation and conflict with one another. Take, for instance, genetic testing in humans, which is now of interest to business (where the dignity of the human person is not a central feature of what is most valued!). The technology of genetic testing can be a useful diagnostic tool. But it provides information about people that is also of interest to others beside their immediate health care providers. Insurance is the most obvious illustration

here (but employers may also become interested in the data). If insurers know the genetic risks of various diseases, they would be able to offer different premiums to different risk groups, and perhaps decide that certain health needs will not be covered at all for some people. (This is already happening for individuals in families with Huntingtons). Thus, a test done for diagnostic purposes, as part of providing health care, may become the means whereby an individual is denied access to future health care. As health insurance and managed care become a larger part of the health provision scene in New Zealand, we will face conflicts between values of providing just health care, for all, and commercial pressures to make a profit – which can be done more easily if high risk people are excluded from coverage. What values will be institutionalised in emerging structures?

Internationalisation of science also brings its own conflicts. Science claims to be an international practice, but obviously in the interface between research and medical care there are strong cultural and ethical influences. When health researchers are participating in collaborative projects with people in other countries, is it acceptable to work with samples collected without fully-informed consent? Is it enough to rely on ethical guidelines of other countries? How should we relate to companies which appropriate the biodiversity of third world and indigenous peoples, or companies that collect and patent blood samples or seeds collected with no regard for ethics or justice? Are one's own values negotiable when dealing with people from another place? Does one have the right to impose one's own values on those in another context?

Such issues remind us that gene technology is not 'just' a scientific tool, but is becoming part of, and integrated into a number of social practices of which science is only one. For instance, gene technology is already having an impact on the practice of food production and distribution. As companies develop and market genetically modified foods (and the chemicals associated with their production) what is grown, and how, is changing. This has implications for biodiversity, for sustainable agricultural practices in different contexts, for control of use of land, for what food is available to whom. Enmeshed in these changes are ethical questions about

who benefits, and who carries the burden of risks? Whose resources and land is being colonised? How do we relate to the land and to non-human life?

Gene technology is also affecting the social practice of reproduction. Other technologies, such as ultrasound, have already increased the amount of surveillance of the health of the foetus, providing women/parents with opportunities to make decisions about whether or not to take a disabled child to term. Genetic testing expands the range of conditions which can be screened for, provides opportunities for information about the baby to be made available to women at risk of bearing a child with a condition such as haemophilia and Huntingtons. At present the conditions tested for are those which are seen as very debilitating or distressing, or life threatening. But such assessments are social judgments about the worth of a child, the meaning of a disability and the significance of a life. Present assessments are already being contested by disability groups and some families affected by genetic conditions. As the range of possibilities extends we will need to decide: What tests will be on offer in future years? What limits will we put on an individual's choice? Is it all right to screen for sex alone (as distinct from screening for a sex-associated disorder)? What if a deaf couple want a deaf child and want to select against a hearing one? If, or when, tests become possible for homosexuality, IQ, predisposition to mental illness or Alzheimer's disease, is it permissible for parents to use such test to select against some foetuses, or to go still further and actively select the most desirable features? Will we provide those tests within the public health system, or will they be available only to those who can pay? What will be our attitudes to those who choose *not* to have those tests and may bring disabled children to birth? Are we going to create a society where *not* to use the technology is to be seen as irresponsible? Our responses to these difficult questions will be an expression of the social values of our communities.

So, some ethical issues raised by gene technology can be addressed within our present ethical frameworks; others will require more work as we bring together conflicting and contradictory practices and social values. But there is another issue underlying these conversations, which is related to my



earlier comparison of gene technology with the Copernican revolution. I will discuss this initially with respect to gene technology in the non-human field, but there are parallels with some potential uses of gene technology with humans.

Gene technology: a conceptual revolution

There is a surprisingly small amount of discussion in the literature on the ethics of using gene technology in plants and animals. Most of the discussion available takes a very utilitarian or consequential approach – a calculation of risks and benefits. There is also an attached (and sometimes fragile) commitment to protecting human autonomy and choice in the uptake of the perceived benefits, as found for example in discussions of labelling of genetically modified foods.

The underlying assumption in many conversations is that if it is (relatively) safe and beneficial (in the short term) then it is ethically permissible/acceptable to use a gene technology. Those who would resist gene transfer across species or kingdom lines, or protest on grounds of culture (both Maori and Pakeha) are reassured that this is perfectly safe, safer than random crossing of closely related species by more conventional means; that there will be benefits, ranging from less use of pesticide to huge crop yield to benefits to human health – all of which may be true.

But to reassure in this way is, I believe, to miss the point of people's resistance to gene technology, and to resist confronting the complexity of ethics at this point in history. Ethics is not just a calculation of risks and benefits, but about what it means to be human, how we understand our place in the world. Ethics is a critical reflection upon those things that are of most importance or of value to us (as individuals, communities and cultures), and may also include an attempt to articulate the framework within which we construct meaning for our lives, and choose, 'how shall we live?'

In previous periods of history, and in different parts of the world today, articulation of the framework or horizon of meaning is not necessary. Values are lived out; ethics is based in an ontology that is accepted, commonsensical within that culture and place. This might be some understanding of God

or of the cosmic order, or some sense of our place as humans within the rest of the world. This ontology, this sense of what is 'given', provides a framework, an horizon of meaning against which it is possible to discern how to live. That framework determines what constraints will be placed, the divide between sacred and profane, the distinction between appropriate and inappropriate.

We may critique some of these practices developed within various ontologies (some have served to reinforce or validate attitudes or social practices that we might wish to change), but we should not dismiss them lightly. They are expressions of cultural norms that bind people together, expressions of community and identity. Many of the boundaries we draw, socially constructed though they may be, are the means by which we understand the nature of the world, and where we fit in – what it is to be human, what are appropriate expressions of our freedom to act, how we understand our relationships with the non-human world.

Public perceptions may be that science is claiming to provide an ontology for our time, but of course science cannot do that. Science can provide us with information about the world, understanding of some aspects of how things function, and some tools with which we can interact with the world. And there is no doubt that the practice of science is influenced by the social world within which it operates. But science does not provide us with our ontology, does not tell us what is of ultimate value, what gives meaning to life. That is a separate project, and one with which Western culture struggles.

Even without gene technologies we struggle with these issues. The modern (or maybe post-modern) predicament is one of a pluralistic world, with multiple world views, and a deconstruction of those structures and assumptions that traditionally provided a framework for our thinking and ethical choices. Gene technology is adding to these difficulties. We discern our ethics, how we should live, within a framework that is a product of our culture, history, place – and the possibilities for action. If we struggle with multiple history and places, it is no wonder that the possibilities for action raised by gene technology are also resisted. They present yet another

source of change and uncertainty. Physical possibilities we thought were given (e.g. possibilities for breeding animals, means of growing food, and how we control disease) are now negotiable. We have new levels of choice to make about how we respond to disease and suffering, what we mean by responsible parenting, how we relate to the non-human world, what level of manipulation and control is appropriate. We need to decide what distinctions are ethically important. This is not a new task, although it takes a new form. We have already constructed distinctions that are peculiar to our time and culture. We have decided that the fact that some animals can feel pain is a reason not to carry out certain types of research. We have re-defined death in the light of new medical technologies (though this is still resisted by many). We are capable of further distinctions.

Is a piece of DNA from a human any different from a piece of DNA from a chimpanzee or a pig or a rat? Shall we make a distinction between naturally occurring twinning and that achieved by embryo splitting? Is there a line to be drawn between genetic manipulation to prevent disease and genetic manipulation to enhance the genetic potential of a child? Scientific explanations of life may blur such distinctions, and can imply they are irrelevant. But just because scientific explanations would de-construct the distinctions, this does not make them insignificant or ethically irrelevant.

Scientists know this. In some of my current research I have been talking with molecular geneticists about their perception of the ethical and social implications of the 'new genetics'. It is striking how often they identify areas of genetic research with which they are uncomfortable. When asked, however, to find reasons for that unease, they struggle. 'It just doesn't seem right or appropriate. Besides, it is not yet technically possible.' But when it does become possible? Should we carry out cloning? germ line gene therapy? genetic enhancement? Is there any basis for a scientist's unease with transgenic higher mammals? Does it matter if our science and technology deconstructs, or appears to make meaningless, all our ways of defining what is 'natural', what makes us 'human'?

The ethical task that faces us is enormous. We are needing to reconstruct

our ethical world and find new ways of understanding the parameters of human responsibility. Just as the theory of relativity required us to re-think how the world was, and forced us to see the world in new ways, so the possibilities of gene technology require us to re-think our ethical landscape. Old approaches may still provide some sort of map around some features of the ethical world (just as quantum mechanics is still useful within some parameters). But we have new challenges to face for which scientific reductionism is insufficient, and traditional ethics is strained.

As we *can* do more and more, the ethical questions become more urgent. If we can, should we? It is important that we think through the ethics, and allow ethics to do that thinking to set the agenda for technology. Otherwise:

It is no longer the progress of science and technology which is being evaluated in the light of morality; it is the validity of morality which is being debated with regard to science and technology. Morality is declared the dependant variable of scientific and technological progress.¹

And that, I believe, is the more challenging ethical aspect of gene technology. Will technology determine our values, or will we be able to use technology to create the sort of world that is consistent with what we value most?

We have fundamentally changed our possibilities for action – moral or otherwise. Not only can we describe the world in ways that were almost unimaginable fifty years ago – we can also act on the world with amazing power. So, if we can do something, should we? We can do lots of things – make health care available only to the wealthy, ration education only to the ‘intelligent’, introduce calicivirus, develop gene technology that will feed the world, enable biological warfare, and/or line the pockets of a few successful business people. But should we? What sort of world do we want to create? These are hard choices – complex choices.

Moral agency

In our science and in our ethics there is a distinction we hold on to – we are not only animals, but also humans. The very abilities that we use to set ourselves apart from the rest of the world are those abilities that make us

moral creatures, ethical creatures. We have the ability to rationalise, analyse, construct, imagine. We are capable of choices, decisions. We are bearers of responsibility for how we shall live and what sort of physical and social world we are participating in creating.

As gene technology (like nuclear technology before it) takes away some physical constraints on our actions, we are left with the need for ethical constraints. ‘Nature’ no longer stops us doing many new things. Like Neanderthal humans before us, we now hold new tools in our hands. We have to decide how to use them wisely, appropriately, ethically. How will we live?

There is, of course, nothing in the discipline of science that qualifies it to make such judgements alone. The public – in all its messy diversity – needs to be involved, and scientists need to find their role in participating in a new discourse, in a new social and physical world. The hard reality is that since ethics are an expression of culture, the public may make choices that scientists would regard as arbitrary. They may make different assessments of risk – in regard to both probability and outcome. They may, as a collective, identify particular limitations they want to put on technology. They may make different choices in NZ, from those made in USA or UK or Japan.

But this is nothing new. We already have constraints on our uses of tech-

nology. We have particular limits on research on animals. There is a bill in the house to ban ectogenesis. We don’t permit genital mutilation of women, or eat live crayfish here.

Gene technology requires us to discern, not as scientists or traders or business people – but as a community. As a recent UNESCO document states in relation to gene technology in humans:

The advances in human genetics require choices to be made which call for the involvement of everyone, because they concern our very conception of ourselves and of our duties and essential rights. These are truly choices that must be made by society. They should therefore be debated by all the constituent parts of civil society, and it is the task of the States, as the guarantors of democracy, to ensure this by taking appropriate action.²

How will we use the new powers that we have – what uses are acceptable, what values will we protect, what values will we construct? I hope the deliberations today will contribute to that discernment.

References

- ¹ Bayertz, Kurt. *Genethics: Technological Intervention in Human Reproduction as a Philosophical Problem*. Cambridge: Cambridge University Press 1994
- ² United Nations Educational and Cultural Organisation. *Draft Declaration on the Human Genome and Human Rights*, July 1997, para 34.

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