Playing Catch-up: Gene Technology and Ethics

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The ethical implications of gene technology are still evolving. The paper highlights some of the issues which societies have to face in the near future, such as human cloning and the notion of personhood and family, the commodification of genetic research and its potential to disadvantage patients, genetic databanks and problems with collecting and storing genetic information and, finally, the validity of promising to feed the starving with genetically modified crops.

Keywords: ethics and biotechnology, human cloning and personhood, genetic databanks and privacy, genetically modified crops

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In the not so distant future, we will choose one genome over another when selecting our embryos for implantation. We will take advantage of genome screens before and after birth to foreshadow predispositions to certain illnesses. We will be able to correct, if necessary, most genetic defects at the earliest opportunity and/or adapt our life style to our genome. Gene therapy will cure millions of people who, at present, have to live with adverse mutations. Stem cell therapy will no longer be seen as unethical as science will succeed in utilising a patient's own cells for therapy. Gene therapy and cloning will become an integral part in the arsenal of medicine We will take new smart drugs, which will have been tailor-made to our specific genetic make-up, minimising or even avoiding harmful side-effects.

The merger of gene technology with nanotechnology will bring additional health benefits. Those who prefer not to undergo gene therapy might opt for nanotechnology to overcome certain physiological or mechanical limitations. Others will use nanotechnology to boost their given genotype or phenotype. The technological capabilities of both gene technology and nanotechnology seem endless.

As all new technologies, gene technology raises numerous ethical issues.

Human Cloning

The completion of the sequencing of the human genome has opened up our possibilities to intervene in nature on a scale and to an extent that has not been possible before. While evolution has taken us to where we are now, we are currently acquiring the tools and abilities to manipulate nature to our perceived advantage.

The birth of Louise Brown, the first human being conceived by in vitro fertilization in July 1978, the arrival of Dolly, the cloned sheep in July 1997 (Wilmut, 1997) and the announcement on 25 November 2001 by Advanced Cell Technology of Worcester, Massachusetts, that it created the first cloned human embryo, are all potential milestones towards cloning a whole human being. These developments could indeed "shake the meaning of life to its very roots" (Molitor, 2002).

Human reproductive cloning is an ethical minefield and many nations such as Denmark, Sweden, the United Kingdom, Germany and others currently have legislation in place banning it. There are several reasons for this.

The first disquiet involves harm, resulting from the risks and uncertainties associated with a procedure that is still experimental and far from safe. Another problem centers on the notion of personhood. Much of our behaviour has a genetic basis, but the genetic basis is complex, as identical, monozygotic twins demonstrate, since they are still individuals. Subtle differences in DNA sequences effect the *pattern* of gene expression and these patterns determine different outcomes. As in music, we have a limited number of notes, but with these few notes we can create infinite different pieces of music. Many believe that a clone is a carbon copy of another person, neither unique nor an individual. This, however, is incorrect. In the same way that each monozygotic twin - nature's natural clone - is a unique person, an "artificial" clone is a unique person also. Like a musician interpreting and shaping a piece of music, a vastly different sociocultural symphony of environmental influences will add a further layer of differentiation, leaving its mark on the developing and maturing cloned child.

A third grey area of ethical debate relates to social identity and kinship ties. Here cloning can create confusion. A cloned child will be an autonomous agent *and* the identical twin to her genome donor a few years removed. Who is the parent - the person who carried her to term, the person whose clone she is, or her grandparents? Who is the grandparent of the child? When the offspring of the cloned person finally reproduce, their children will also be related to the genome donor. Thus, with a single act of cloning, our understanding of family relationships needs re-evaluation. The novel family constellations will be problematic in those cultures, where lineage identifies responsibilities. There are additional stressors. For example, the clone can evaluate her own medical future simply by observing the genome donor. With what burden? Although genes are *not* deterministic, they are nevertheless influential. The cloned child neither consented to its existence nor to the genome donor her creators chose for her. At issue is, therefore, not only the question of benefit, harm, and family relationships, but doubts about the permissibility of assumed consent.

The cloned child will need to cope with more. Inevitably, an "artificially" cloned person will be compared to the adult from whom he was cloned. The child might feel that he has been denied his individuality. Parents, for example, might choose to educate their cloned child according to the demonstrated abilities of the person who was the genome donor, but the child might not fit that picture. What happens when the child

does not live up to his family's expectations? Will his family's deterministic belief in the power of genetics limit the cloned child's right to an open future?

Will humans "control...evolution" (Molitor, 2002)? Will human reproductive cloning lead to a new branch in human evolution? Unlikely. Cloning will not produce a separate human species, for the simple reason that the number of artificially altered individuals will remain minuscule in global terms. Their numbers will remain stray notes in the musical expression of life.

This contrasts starkly with the possibility that genetics could become the driving force behind a new division in society. At the top of the new pyramid will be the genetically enhanced people, perhaps including individuals who not only have a 'superior' genetic make up, but also might have additional, non-genetic enhancements. At the bottom of the pyramid will be the "naturals", the unaltered individuals, including those who are disabled. Unless we develop and nurture our sense of caring and mutual responsibility, unless we forge ethical relationships with all stakeholders, our societies will become vastly more unjust, cold, uncaring communities, where discrimination and stigmatisation is rampant.

Such outcome is not inevitable and there are plenty of positive developments accompanying the exploitation of data coming from the Human Genome Project. For one, our current perception of a race might disappear. There is no biological basis for it. The Human Genome Project demonstrated that races do not seem to distinguish themselves by their genomes. As we move through the 21st century the concept of 'race' will be weakened further as continuous waves of human migration and intermarriages will see the phenotypical differences gradually disappear. Secondly, it is hoped that we also revise our understanding of disability. As more and more information about genes and their interplay with nature filters out into the general population, it will become obvious that all of us harbour gene sequences that disadvantage us. We are all disabled in some way. Therefore we should focus on our genetic strengths rather than on our genetic weaknesses.

Commercialisation of Genetic Research

Human reproductive cloning is inevitable and controversial. No less controversial is the merger of genetic science with business.

Ten years ago, science was still a supremely social institution, reflecting and reinforcing the dominant values and views of a given society.

Science used methods that were objective and non-political, true to facts and evidence.

Today this description seems to be at odds with reality, because science now lobbies politicians and industry to ensure funding in a climate of dwindling resources for research and development. Scientists today have to be entrepreneurs first and researchers second. They now have to compete in the market place of the biotechnology industry, which is expected to be a key driving force in economic growth over the next 30 years. As a result, in countries like Australia, public funding bodies presently evaluate any grant application by looking first and foremost at its potential to attract intellectual property rights, such as patents, copyright and know-how.

The changeover from an inward-looking laboratory based science to an outward-looking science that pursues its craft as a business endeavour began with the race to decipher the sequence of the human genome and the possibility to patent gene sequences. It became a race between the publicly funded Human Genome Project and the privately funded sequencing effort of Celera. The race to sequence the human genome quickly transformed itself into a race to patent gene sequences. It has placed biotechnology firmly in the midst of competing markets. The fierce competition has changed scientific culture from one of openness and free exchange of information, to one of secrecy and ownership of information.

In the public sector today researchers and their institutions have to be mindful of premature disclosure. Any disclosure prior to filing a patent application may now threaten the subsequent granting of that patent - and the financial rewards that might follow. Disclosure could include a statement in a conference abstract or proceedings, a manuscript, a simple statement in an institutional annual report or even a verbal statement made during a seminar or workshop. How detrimental will the withholding of information be for patients?

The commercial reality is such that biotechnology and pharmaceutical companies are forcing the pace and direction of research. Competition in the market coupled with huge up-front investment dictates that these companies channel their research and development money primarily into areas that promise the quickest and highest return. Patients with less 'profitable' diseases will miss out even further.

Thirdly, biotechnology with its current emphasis on the commodification of knowledge constantly battles with the notion of conflict of interest that can compromise the validity and safety of research. A possible conflict of

interest can be serious, as exemplified in September 1999, when the enthusiasm for gene therapy came to an abrupt halt with the death of 18-year old Jesse Gelsinger, the first patient to die from adverse effects during a clinical trial. Conflict of interest was one of the contributing factors.

Genetic Databases

Increasingly, human genetic information and genetic samples are being collected and stored in human genetic databases and genetic registers and maintained by hospitals, pathology laboratories, and public and private research organisations. In the US alone in 1999 approximately 282 million tissue specimens were stored with new samples being added at a rate of 20 million per year (Barlow-Stewart, 2001). These depositories constitute an invaluable resource for research, counselling, and treatment (Gesche, 2001). Privacy and confidentiality concerns are raised if the information and the samples are not properly protected. Breaches of privacy and confidentiality could lead to the discrimination and stigmatisation of people, particularly in the area of employment and insurance. Unfortunately, in our high tech environment, no databank is safe from intrusions.

A second issue is consent. Who is allowed to collect and store samples and genetic information? How and for how long should samples and the information be stored? Who has access to it and for which purposes? Can the information and the samples be used for purposes other than the initial one? Is it prudent to ensure that the DNA samples are not used for more extensive genetic testing at some time in the future as we learn more about our gene sequences? Should additional testing require the renewed consent of the original donor? How do we know that informed consent is being sought? Who is the person leading the informed consent process and how well trained in genetics and genetic counselling do we want him or her to be? The regulations and legislation to these questions are different from country to country. So are the quality control processes. There are other uncertainties. How are the samples being processed? Are quality control processes in place? How do we secure accountability and public scrutiny?

Molitor (2002) mentions Iceland's Genomic Database that is being maintained by deCODE Genetics, a for-profit company. deCodes database provides for an unprecedented amount of paired phenotypic, genotypic and genealogical information. Its data can be used in searches for

disease genes, in the management of health and disease, for outcome measures, and for managing resources in the healthcare system. According to Greely (2000) Iceland's genomic database is seriously flawed for several reasons. It is connected to a for-profit firm, which has exclusive control over the databank, it lacks an affirmative informed consent process for the collection and storage of data, and it has no proper privacy provisions for individuals (ibid).

Genetically Modified Crops

Genetically modified (GM) crops can be defined as crops in which the genetic material (DNA) has been altered in a way that does not occur by natural recombination.

Some of the benefits listed for GM crops include insect resistance (eg. cotton, corn, field peas), herbicide resistance (eg. canola, soybeans, subterranean clover), disease resistance (eg. barley, rice, tomatoes, bananas, potatoes), quality enhancement (eg. long shelf-life tomatoes, more digestible soybeans, healthier oils from canola, better feed qualities in corn, coloured cotton, improved flavour of strawberries), edible vaccines (measles, HIV), and higher-yields (walnut, strawberries, rice, canola, soybeans, corn).

Environmental activists and consumer support groups, on the other hand, claim that widespread growing of GM crops will lead to selection pressure on insect populations and the arrival of even hardier pests. Furthermore, opponents fear a loss of biodiversity, particularly in third world countries, gene pollution through outcrossing into nearby crops or weeds, and numerous social and economic 'risks'.

It has been argued that GM crops will feed the world and that they will do so in a manner that is environmentally sustainable. Opponents claim that these arguments are not valid. They argue instead that both the prevalence of chronic hunger and GM crops will not alleviate malnutrition among the world's population.

The Food and Agriculture Organization (FAO) estimates show that in 1999 the world produced 2,780 calories of food per person, well above the average adult requirement of 2,350 calories. So why do so many people starve? Mainly for three reasons: purchasing power - people are too poor to buy food, poor agricultural production, and poor to non-existing infrastructure needed to evenly distribute food products. Can we expect giveaways to poor countries (Molitor, 2002)? Yes, one would hope so. Ge-

netically modified plants can certainly bring nutritional benefits, and the golden rice seems to be one example. However, the benefit will only be a true benefit, when its introduction does not come at the expense of loosing the ownership over local staple food resources and when it does not lead to an increase in economic inequality and dependence.

Can GM crops reduce poverty? Lowering the prices for foods and devising seeds for specific environmental/soil conditions or improving their storage capacity could reduce poverty, but will it? The outlook here is not promising. The private sector corporations, which currently dominate agricultural biotechnology, need to recoup their investments on research and development. Thus, they need to sell their products at the highest possible price. That leaves the questions: who will produce genetically engineered seeds for the poor? There does not seem to be anyone. Free give-aways can only be temporary.

Conclusion

We stand at an unprecedented juncture in human history. As we unravel our biology and learn to manipulate it, we are seizing control of our evolution and moving into the unknown. The breakthroughs coming from biotechnology will challenge our most fundamental values and beliefs. They promise (some would say threaten) to eventually transform us. At the very least, the rapid advance of molecular genetics will force us to consider the question of what it means to be human.

Looking back at history, we have been confronted on many occasions with undesirable consequences arising from new technology. Every new technology brings with it new challenges and risks. But, on balance and when handled correctly, technology has propelled humanity towards greater health and prosperity. Significant technological and scientific advances have always far outweighed the risks associated with them. This will also be the case for biotechnology, *provided* we move forward with honesty and with far more caution.

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