

MORALITY MORTALITY

Will modern medicine kill our respect for human life?

BY SUE MARTINUK

FOR MORE THAN A DECADE, scientists collaborated in a massive, worldwide research endeavour to decipher the genetic code that controls the creation and development of human life. The HUMAN GENOME PROJECT (HGP) produced the first map of this code in 2003, ostensibly revealing the very mysteries of creation itself. Indeed, some scientists claim that this knowledge is the key to enter a biological utopia where science is capable of manipulating human life, curing disease and perhaps even conquering death itself.

The discovery was one giant step forward for science, but there remains tremendous uncertainty as to whether it represents a step forward for mankind. The goal of healing and even eliminating disease has positive implications, but as society gains more knowledge about how that is accomplished, it is evident that we are unprepared to deal with the ethical, medical, legal and societal issues that represent the inevitable consequences of genetic technology.

One question lies at the core of all these issues: How will the power to manipulate the human genome affect our respect for human life, including our attitudes toward, and support for, those who are born with genetic anomalies that lead to diseases and disabilities?

THE POWER OF GENETIC TECHNOLOGY

The HGP has contributed to the exponential growth of a new science called human GENOMICS (the study of the human genome). GENES that control the onset of breast cancer, cystic fibrosis, Huntington's disease, muscular dystrophy and a host of other diseases have been discovered, and at least 250 genetic diseases (the number is growing rapidly) can now be detected by genetic testing.

Genetic technology can be combined with reproductive technologies (termed REPROGENETICS) to ensure or prevent the inheritance of a particular gene. For example, a couple who suspects they may pass on defective genes to their children may choose to utilize reproductive technologies (such as IN VITRO FERTILIZATION) to create embryos that can be screened for genetic mutations using PRE-IMPLANTATION GENETIC DIAGNOSIS (PGD). If the embryos are free from mutations, they are implanted for pregnancy. But if genetic abnormalities are detected, the embryo is discarded or used for research.

Such destruction or experimentation isn't problematic to those who view embryos as mere biological waste. But if one accepts that human life begins at conception, then these options are highly objectionable and diminish mankind's respect for all human life. After all, if society accepts the use of genetics as biological criteria to determine who should live or die (even in an embryonic stage), it then implicitly 1) creates societal conditions/attitudes that devalue the lives of those who live with genetic abnormalities or disease, 2) allows a high-tech EUGENICS policy to take root and, 3) pushes mankind further down the path of biological re-creation. After all, the selection of only healthy embryos may, over time, eliminate the

THE HUMAN GENOME PROJECT (HGP): an international, collaborative research effort to sequence and map the human genome. It was completed on April 14, 2003. (<http://www.genome.gov/10001772>)

GENOMICS: the study of genes and their functions. It addresses all genes and their interrelationships in order to identify their combined influence on the growth and development of the organism. (<http://www.who.int/genomics/geneticsVSgenomics/en/index.html>)

GENES: the functional and physical unit of heredity. Genes are pieces of DNA, and most genes contain the information for making a specific protein. (<http://www.genome.gov/glossary.cfm?key=gene>)

REPROGENETICS: the merging of reproductive and genetic technologies; these combined technologies will become more common in the near future as techniques like preimplantation genetic diagnosis become more available and more powerful. (<http://en.wikipedia.org/wiki/Reprogenetics>)

IN VITRO FERTILIZATION: a technique in which egg cells are fertilised (combined with sperm) outside the woman's body. (http://en.wikipedia.org/wiki/In_vitro_fertilization)

PREIMPLANTATION GENETIC DIAGNOSIS (PGD): a method to examine the genetic material of eggs prior to fertilization or embryos before they are implanted in the uterus. (http://en.wikipedia.org/wiki/Preimplantation_genetic_diagnosis)

mutant gene and its resulting disease, effectively re-engineering man's genetic code.

All of these consequences become possible once we accept genetics as the sole determiner of the value of life.

Prenatal genetic screening (analyzing the genetic material of the unborn) includes the use of enhanced forms of ultrasound, amniocentesis and chorionic villus sampling to detect errors in the biological machinery of an unborn child. These capabilities may allow doctors to treat disease in utero or as soon as the child is born. One such example is retinoblastoma, an extremely rare eye cancer that can be hereditary. If detected in utero, treatment immediately after birth can prevent loss of eyesight. But such treatments are rare. For the vast majority of diseases, the predictive technology is far more advanced than any treatment options, and gene therapies that would, in theory, allow researchers to correct anomalies (perhaps by inserting a "normal" copy of the gene) remain largely unproven.

In more than 80 per cent of cases, the pregnancy is terminated when genetic abnormalities are found,¹ but termination rates do vary with the diagnosis. Abortion rates range from 64 per cent for spina bifida (which has varying degrees of severity) to 84 per cent for anencephaly (where the child will die shortly after birth) and 92 per cent with a diagnosis of Down syndrome.² These statistics closely reflect the Canadian situation, although rates do vary from province to province³ and from country to country.⁴ This determination to eliminate the imperfect is particularly disturbing when one considers that about 5,000 genetic diseases exist and we each possess at least five gene mutations.

CONCERNS

Advances in biotechnologies have already had a significant impact in determining how we reproduce, whether we reproduce and what kind of child we want to produce. We may support the personal right of individuals to make such choices, but their collective impact now radiates beyond hospital treatment rooms to the public square where it has substantially altered our perception of humanity, giving rise to the following legitimate ethical and moral concerns:

1 *Creating a genetically-engineered race:* There is considerable speculation that broad acceptance of genetic screening, coupled with advances in the understanding of gene function, will lead to an all-out quest to gain control over every aspect of a child's destiny. This would include, for example, all genetic characteristics, height, sex, athletic and musical abilities or intelligence.⁵ Genetic engineering would create a societal divide between genetically enhanced and non-enhanced humans and, as it becomes more common, there will be tremendous pressure on all couples to only give birth to genetically-enhanced, disease-free children.⁶

This scenario represents the worst fears of bioethicists and luddites, but it is not likely to become a reality anytime soon. These fears are primarily based on the presupposition that complex physical characteristics and attributes are controlled by individual genes, a theory that was widely accepted when it was estimated that the HUMAN GENOME consisted of

at least 100,000 genes. But the HGP proved that there are only about 30,000 genes, suggesting that rather than having individual roles, many genes must have multiple functions or act in combinations or groups. When multiple numbers of genes are involved, the manipulation of one gene could have an untold number of repercussions on other genes.

The idea that we will be able to use genetics to manipulate the characteristics of man is theoretically possible, but not in the near future. The HGP has determined the physical positions of genes on chromosomes, but it will take decades to determine all gene functions and interactions.

In the meantime, focusing discussion on manipulating genes to suit our egocentric or most vile purposes has created a distorted perception of what genetics can realistically achieve. More disturbing than that, it has distracted us to the point where we have virtually ignored the current impact that genetics has on our society.

2 *Rising expectations that the imperfect should not be born:* A far greater threat to the public good is the current use of genetic technology to screen embryos (in vitro) and unborn children (in utero) for GENETIC ANOMALIES, with the ultimate goal of discarding/terminating them if any are found. As stated above, this often results in the destruction of embryos based on minute imperfections that, until now, have been an accepted part of the genetic gamble of reproduction. Allowing this procedure to continue on a broad scale is precipitating an indistinct, yet profound, transformation of health care from a reactive model (of treating disease based on symptoms) to a proactive model (of predicting and eliminating disease based on genetics).⁷ This transformation not only threatens to lead to the wholesale destruction of human embryos, but also to a diminished respect and support for those who are afflicted, and live with, genetic disease.⁸

The expectations of parents are already shifting. Many feel there is no longer any reason to leave the genetics of the unborn to chance, and they are increasingly feeling obligated to utilize the technology and only give birth to a fully healthy baby. This thinking fuels a greater use of technology and eventually creates a spillover effect to the public—whereby the public expects parents to use technology to ensure that only healthy children are born. Should this expectation become entrenched, society's tolerance for individuals with any genetic imperfections will diminish, as will societal and even

EUGENICS: a social philosophy which advocates the improvement of human hereditary traits through social intervention. (<http://en.wikipedia.org/wiki/Eugenics>)

HUMAN GENOME: the genetic material that directs the development and growth of the human species (Homo sapiens). The human genome consists of about 30,000 genes located on 23 chromosome pairs that reside in each human cell.

GENOME: an organism's complete set of deoxyribonucleic acid (DNA), a chemical compound that contains the genetic instructions to control the growth and development of that organism. (<http://www.genome.gov.11006943>)

GENETIC ANOMALIES: mutations that occur in the DNA of a particular gene and alter the function of the gene. As a result of mutations, genes send the wrong information to the body, resulting in varying degrees of disease or dysfunction. (<http://www.primto.it/pediatric-rheumatology/information/UK/13.htm>)

medical support. After all, some may say, “Why should society cover the extensive costs of a lifelong disease if the parents had an opportunity to make sure their baby was born healthy?”

This intolerance will continue to foment in circular fashion: As potential parents view society’s intolerance and diminishing support, they will increasingly view screening technology (and termination if defects exist) as a necessary component of human reproduction, and so the cycle continues.

3 *A growing tendency to define human behaviour through science alone:* Media reports have widely proclaimed the discovery of genes or “genetic links” that may be responsible for human behaviours/traits such as happiness, obesity, sexuality and even infidelity. But most of these studies have yet to be corroborated, and it is well-accepted among scientists that complex human behaviours/traits will be linked to interactions among various genes, rather than the product of individual genes.

Media reports tend to focus more on the potential of such discoveries than on the scientifically-valid details and applications. Such spin has fuelled societal and/or non-academic speculations that our behaviours and actions may be dictated more by genetics than by our environments and personal choices, thereby suggesting that man is little more than a pre-programmed genetic machine who has little control over his own actions.

This interpretation of gene function led to the creation of a philosophy called “transhumanism” that advocates taking control of human evolution through gene modification.⁹ But, more than that, it fosters a strictly science-driven understanding of mankind that equates man with other members of the animal kingdom. In doing so, it ignores the distinctly human attributes that define us and enable us to rise above the simple evolutionary strategies of the animal kingdom: the will (to choose our actions), the intellect (to reason), the conscience (to understand right from wrong) and the soul (the intangible, spiritual nature of man).

4 *Genetic technologies may be implementing eugenics policies via individual choice:* Given the potential of genetic technology to manipulate human life, there are legitimate reasons for society to govern its use. Yet Canadian society currently affords absolute value to individual rights, including the right to “absolute reproductive freedom.” Consequently, there is little public will to interfere with/regulate individual decisions to terminate a pregnancy or discard an embryo. But as G.K. Chesterton has written, “To have a right to do a thing is not at all the same as to be being right in doing it.”¹⁰

Thousands of individual decisions to eliminate diseased embryos and fetuses may already be subtly establishing an unstated, laissez-faire-style eugenics policy that medicine and society are inadvertently accepting. According to Dr. Margaret Somerville, a bioethics professor at McGill University, our ready recognition of individual rights to make such determinations has essentially allowed “...an outcome that would never be acceptable as public policy [to be] implemented through the accumulation of individual choices.”¹¹

5 *A shift from sanctity of life to quality of life as the basis for medical decision-making:* Perhaps the greatest concern (and one that is at the core of all other concerns) is how the new genetics has subtly diminished our respect for human life. In the past, this respect was based on the fundamental principle that all humans are created equal and have equal value, regardless of their abilities and capacities. Genetic technology is pushing both doctors and society to shift from this ethic to a more subjective understanding of “personhood.” Under this supposedly ethical principle, only some individuals have rights and humans must possess certain cognitive capabilities, be fully conscious and capable of acting autonomously to be deemed legal “persons” with rights and moral value.¹²

Human embryos and fetuses are not “persons,” and therefore, society has no moral obligation to protect them. The increasing acceptance of this theory has given genetic technology free reign to seek out genetic errors and eliminate embryos or fetuses that possess them.

Our wildest fears of genetic engineering may never come true, but our worst fears of the deconstruction of humanity may have already come true. The 21ST century notion that humanity is both subjective and selective is no longer contained to the realm of science.

In medicine, this understanding of humanity is clearly leading to a model of care that directly contravenes the spirit and understanding of the Hippocratic Oath. This oath has traditionally governed a physician’s duty to care for the sick and uphold the sanctity of life, but some applications of biotechnology are now leading physicians to focus on quality of life instead of sanctity of life.¹³

In the public square, it has precipitated and fuelled a philosophical trend in which society judges technology on the basis of an individual’s “right” to use it rather than society’s obligation to give equal value and respect to all human life.

Both consequences are to be expected when the miraculous is reduced to mere scientific methodology. Conversely, redirecting discussions from their current emphasis on individual rights to a new focus on the uniqueness of human life may act to stem the tide of diminishing respect for humanity. This shift is possible because many of the above presumptions are not yet well-entrenched in mainstream society.

SOCIETY’S RESPONSE

The discussion must shift from individual rights to what is best for society at large. The common good can best be ascertained outside the realm of rights by asking the simple questions, “Is this inherently wrong?” and “Does it respect human life?”¹⁴ Only then, once we have assessed its moral good, can we decide if – and in what circumstances – it is ethical to proceed.

Most members of society still experience a sense of compassion and respect for those who are disabled or suffer from disease. We may silently allow the unborn to be eliminated based on faulty genetics but, on a personal level, it is anathema for most of us to look at a newborn child or someone suffering from cystic fibrosis and believe that they are any-

thing but fully human and fully alive. Their courageous lives inspire our understanding and respect for the innate strength and depth of the human spirit.

Such experiences demonstrate the intrinsic value that is associated with caring for one another. All individuals, at some point, are placed in the position of either receiving or giving care, from or to family, friends or loved ones. Most of us have a subconscious recognition that our own lives will be impoverished if we cease to care – whether that be in the most practical sense of the word or by giving in to the notion that some are less human or less valuable than others.

New technology that gives us an unprecedented view of fetal development also inspires public respect and understanding for the humanity of embryonic life. Ultrasound images of fingers and toes; kicking and jumping; thumb sucking and responding to familiar voices all make it difficult to deny that the fetus is fully human. The enhanced and evolving recognition of fetal rights in the United States demonstrates that there may still be opportunity to educate individuals about the intrinsic value of the unborn – before they make decisions about genetic screening.

An individual’s right to a unique genetic identity must be upheld. This argument is typically used in the cloning debate,¹⁵ but if an individual’s right to natural genetic diversity governs the use of cloning technology, then it should also govern genetic screening. The recognition and application of this right upholds genetic diversity as a positive component of human life, and suggests that alterations to one’s genetic code are to be celebrated rather than disparaged.

We must act to preserve the rights of the disabled in all aspects of medical care and societal support. Advocates for the disabled, families of those afflicted and the disabled themselves must become principle stakeholders in discussions about how to use this technology and how to deal with its medical, ethical, legal and social implications. Decisions about medical care are increasingly being driven by a perceived belief that a scientific imperative exists (“If we can do it, we should do it”) and the idea that the use of genetic technology to identify and eliminate man’s genetic imperfections is inherently right. Those faced with the prospects of utilizing genetic technology should be obligated to hear from stakeholders, including the genetically disabled.

CONCLUSION

“The road to genetic hell could be paved with good scientific intentions.”¹⁶

Indeed, our society seems too content to let technology push the ethical boundaries of medicine because we believe that it will ultimately lead to our benefit and comfort. But, as suggested throughout this article, the road to achieving this end is much longer and more complicated than that. It is a path that inevitably leads to the ranking, devaluing and discarding of our fellow humans, even while the dream of gene therapies for genetic diseases may never be successfully realized.

Sickness and imperfection are as much a part of life as the joy we take in living. We will surely become a less civilized society if we allow modern medicine to descend into an institution that views life and treats individuals on a strictly utilitarian basis. After all, allowing medicine to take the lives of the imperfect and the sick will surely establish a hierarchy of value in which, at some point, we will all be found lacking.

RESTATEMENT OF THE OATH OF HIPPOCRATES

I swear in the presence of the Almighty and before my family, my teachers, and my peers that according to my ability and judgement, I will keep the Oath and Stipulation:

To reckon all who have taught me this art equally dear to me as my parents and in the same spirit and dedication to impart a knowledge of the art of medicine to others. I will continue with diligence to keep abreast of advances in medicine. I will treat without exception all who seek my ministrations, so long as the treatment of others is not compromised thereby, and I will seek the counsel of particularly skilled physicians where indicated for the benefit of my patient.

I will follow that method of treatment which according to my ability and judgement I consider for the benefit of my patient and abstain from whatever is harmful or mischievous. I will neither prescribe nor administer a lethal dose of medicine to my patient even if asked, nor counsel any such thing, nor perform act or omission with direct intent deliberately to end a human life. I will maintain the utmost respect for every human life from fertilization to natural death and reject abortion that deliberately takes a unique human life.

With purity, holiness and beneficence I will pass my life and practice my art. Except for the prudent correction of an imminent danger, I will neither treat any patient nor carry out any research on any human being without the valid informed consent of the subject or the appropriate legal protector thereof, understanding that research must have as its purpose the furtherance of the health of that individual. Into whatever patient setting I enter, I will go for the benefit of the sick and will abstain from every voluntary act of mischief or corruption and further from the seduction of any patient.

Whatever in connection with my professional practice or not in connection with it I may see or hear in the lives of my patients which ought not to be spoken abroad I will not divulge, reckoning that all such should be kept secret.

While I continue to keep this Oath unviolated may it be granted to me to enjoy life and the practice of the art and science of medicine with the blessing of the Almighty and respected by my peers and society, but should I trespass and violate this Oath, may the reverse be my lot.

endnotes

- 1 Dr. A Chudley (personal communication). Medial Director, Genetics and Metabolism and Professor, Pediatrics and Child Health/Biochemistry and Medical Genetics. University of Manitoba, Winnipeg, Manitoba.
- 2 Mansfield, C. et al. (1999) Termination Rates after Prenatal Diagnosis of Down Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A Systematic Literature Review. *Prenatal Diagnosis* 19: 808-812. 1999.
- 3 Dr. A Chudley (personal communication).
- 4 Mansfield, C. et al. (1999) Termination Rates...
- 5 Silver, L.M. (2000) Reprogenetics: How do a Scientist’s own Ethical Deliberations Enter into the Process? *Humans and Genetic Engineering in the New Millennium*. Copenhagen: Danish Council of Ethics.
- 6 Silver, L.M. (2000) Reprogenetics...
- 7 Bernstein, A. (2001, February 14) Balancing Act: Science and Society. *The Globe and Mail*, p. A13
- 8 Smith, W.J. (2000, April 3). Is Bioethics Ethical? *The Weekly Standard*.
- 9 Smith, W.J. (2002, September 20). The Transhumanists: The Next Great Threat to Human Dignity [Version électronique]. *National Review*, Disponible à <http://www.nationalreview.com/comment/comment-smith092002.asp>.
- 10 Chesterton, G.K. (1917). *The War of the Usurpers. A Short History of England*, London: Chatto and Windus Ltd.
- 11 Somerville, M. (2002, October 10). New genetics functions as eugenics. *National Post*, p. A22
- 12 Smith, W.J. (2002, September 20). The Transhumanists...
- 13 Irving, D. (2001, May) The Bioethics Mess. *Crisis*
- 14 Somerville, M. (2001) *The Ethical Canary: Science, Society and the Human Spirit*. Toronto: Penguin Canada.
- 15 Somerville, M. (2001) *The Ethical Canary...*
- 16 Pinkerton, J. (2000, July 10) *Scripps Howard News Service*.