

Setting Limits: Medical Technology and The Law

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1. Introduction

In the May 1959 Rede Lecture at the University of Cambridge, CP Snow articulated his thesis that contemporary society is composed of two competing or clashing cultures: the (literary) intellectuals and the scientists.¹ Since science is not a subject presented easily to the public through literature (for example, journals, books, newspapers, magazines), the self-proclaimed intellectuals ignore the value and importance of the ideas science seeks to promote. Thus, the scientific ethic remains largely invisible as an understandable intellectual activity.²

In the second edition of *The Two Cultures*, published in 1963, Snow suggests the emergence of a new third culture which will close the communication gap between the intellectuals and the scientists and would thus be seen as new public intellectuals or synthesisers.³ They will be interpreters of the ideas and values of the continuing scientific revolution.⁴

The central purpose of this paper is to question the extent to which law can assume an active role as a third culture in complementing and translating, if not blending, the other two cultures — all in an effort to provide a framework for principled decision-making for complex biotechnological and medical issues in the 21st century. Is this task too daunting for law?

Grant Gilmore observed that ‘the body of the law, at any time or place, is an unstable mass in precarious equilibrium’.⁵ US Chief Justice Warren E Burger observed that ‘[t]he law does not search out as do science and medicine; it reacts to social needs and demands’.⁶ And, in Australia, in 1970, long before the pace of medical and biotechnological science had quickened to the level it is today, Justice Windeyer opined that the law was not keeping pace with medicine and, indeed, marched ‘in the rear’, limping along.⁷

Today, these three observations have relevance and, indeed, shape the contours of this paper. More specifically, they raise informed caveats to the feasibility of a

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1 Charles P Snow, *The Two Cultures and the Scientific Revolution* (1959).

2 *Ibid.*

3 Charles P Snow, *The Two Cultures: And A Second Look* (1963).

4 *Ibid.* See generally John Brockman (ed), *The Third Culture: Scientists on the Edge* (1995).

5 Grant Gilmore, *The Ages of American Law* (1977) at 110.

6 Warren E Burger, ‘Reflections on Law and Experimental Medicine’ in George P Smith, II (ed), *Ethical, Legal and Social Challenges to a Brave New World* (1982).

7 *Mount Isa Mines Ltd v Pusey* (1970) 125 CLR 383 at 395 (Windeyer J).

full partnership between medical technology and law as the new Age of Science develops in this, the 21st century.⁸ At the same time, they raise a level of needed concern for the social effects of legal institutions, legal precepts and legal doctrines as they interplay with developing medical technologies.⁹ For cosmic utopians, medical science and technology are seen as forces to achieve a 'total liberation of mankind'.¹⁰ Contrariwise, catastrophists suggest, with alarm, that the limits of science have been met already.¹¹

2. *Macro Standards of Evaluation*

Two levels of analysis must be pursued in order to test whether limitations should be imposed upon medical science. One level involves a macro, or aggregate, evaluation of the uses and effects of medical technology and the other, a micro, or individualised, evaluation of the applications of this technology. At the macro level of consideration the central inquiry is: Should scientific discovery be given unlimited licence or should it be restrained? At the micro level, the question becomes: How should the benefits of medical technology be parcelled out or rationed?

No doubt one of the foremost Australian jurists of his day, Julius Stone, addressed the issue of social responsibility in science in a 1973 lecture entitled, 'Knowledge, Survival, and the Duties of Science'.¹² He advanced the proposition that 'scientists have a duty to exercise self-restraint in pressing further those scientific activities which manifest' a likelihood that they will result in 'limit situations' or, in other words, 'dangers of cataclysmic physical or psychological proportions for mankind as a whole'.¹³ Scientific self-restraint should be imposed only when a scientist is 'clearly able to foresee that the particular line of work is leading to a kind and scale of dangers constituting a "limit situation"'.¹⁴ While acknowledging a predisposition 'in favour of the traditional freedom of the science',¹⁵ Stone had grave reservations about the feasibility of *in vitro* fertilisation as well as genetic surgery and engineering.¹⁶ He viewed such interventions as 'formidable dangers to a liberty-based society ...'.¹⁷ Today, Stone would, no doubt, be classified as a middle-of-the-road cosmic utopian *and* catastrophist; one willing to embrace the wonders of science, so long as they do not endanger mankind at the cataclysmic level.¹⁸

8 See generally Michael Kirby, 'Law Reform as "Ministering to Justice"' in Anthony Blackshield (ed), *Legal Change: Essays in Honour of Julius Stone* (1983).

9 *Ibid.*

10 George P Smith, II, *The New Biology: Law, Ethics, and Biotechnology* (1989) at 1–13.

11 *Ibid.* See Arthur L Caplan, *Am I My Brother's Keeper? The Ethical Frontiers of Biomedicine* (1997) at 190–193.

12 Julius Stone, 'Knowledge, Survival, and the Duties of Science' (1973) 23 *American U LR* 231.

13 *Id* at 240.

14 *Ibid.*

15 *Id* at 258–259.

16 *Id* at 258.

17 *Id* at 258.

18 See generally George P Smith, II, 'The Province and Function of Law, Science and Medicine: Leeways of Choice and Patterns of Discourse' (1987) 10 (2) *UNSWLJ* 103.

A. *Ethical Relativism?*

In order to guide scientific study and advancement, a standard of ethical relativism is suggested; one which recognises that moral values are in no way absolute, but rather determined by certain variables 'usually of social phenomena'¹⁹ and a standard which nevertheless incorporates the value of ethical responsibility.

Others have suggested that ethics is neither relative nor subjective.²⁰ Rather, it is asserted, ethical conduct is universal and forces the individual — in this present context of analysis, the medical scientist — to choose a course of action that has the 'best consequences', on balance, for all affected.²¹ In a very real way, then, this approach advocates a form of utilitarianism. Yet, it is different from classical utilitarianism in that 'best consequences' is defined as what, 'on balance, furthers the interests of those affected, rather than merely what increases pleasure and reduces pain'.²²

Rather than be straight-jacketed by an a priori ethic of the type Stone advanced, which would have the practical effect of ceasing the development of scientific knowledge in many areas, what is needed is an ethic shaped by the particular situation of present investigation.²³ Such an ethic recognises the needs of the medical and biotechnological sciences to provide humane and technologically appropriate (that is, reasonable) care for the sick and minimise human suffering, prizes the value of genetic improvement and the corresponding elimination of inheritable disease,²⁴ as well as embracing an understanding of the need for economic fairness in the distribution of the benefits of science.²⁵ The situation ethic is grounded in an ungirding or inherent force which directs ultimate actions be undertaken with love, kindness and humanness which, in turn, advance and preserve human dignity.

3. *The March of Science*

Medical technology is so uniquely powerful that its impact is felt not only in daily life, but also in the way life is viewed. For example, the technology of mechanical ventilators, combined with heart transplantation, brought a societal re-examination of how death should be defined and led to the conclusion that the death of the entire brain is equivalent to, for all purposes, death of the whole person. This new

19 Julius Stone, *Human Law and Human Justice* (1965) at 227–262.

20 Peter Singer, *Writings on an Ethical Life* (2000) at 9–11.

21 *Ibid.*

22 *Id.* at 17.

23 See generally Joseph Fletcher, *Moral Responsibility: Situation Ethics at Work* (1967).

24 George P Smith, II, 'Genetic Enhancement Technologies and the New Society' (2000) 4 *Medical Law International* at 85; George P Smith, II, 'Eugenics and Family Planning: Exploring the Yin and the Yang' (1984) 8 *U Tas LR* 4 at 4–6.

25 George P Smith, II, *Genetics, Ethics and the Law* (1981) at 2. See also George P Smith, II, 'Biomedicine and Bioethics: *De Lege Lata, De Lege Ferenda*' (1993) 9 *J Contemp Health L and Policy* 233; George P Smith, II, 'Manipulating the Genetic Code: Jurisprudential Conundrums' (1976) 64 *Geo LJ* 697.

definition, in turn, allowed the ‘harvesting’ of hearts and other vital organs from individuals who, although dead under a brain death criteria, continued to have both circulation and respiration maintained artificially by medical ventilation.²⁶

While Americans might decide to limit ‘halfway’ or exotic, science-fiction inspired technologies, such as artificial hearts or brain transfers into robot bodies, it would appear unlikely they would ever approve limitations on medical research whose focus is to discover technologies, drugs, and scientific techniques which not only maintain qualitative existence, but extend life. The reason for this position is simple and direct: ‘there is no coherent argument for arbitrarily ending a life that could be prolonged with reasonable quality at a reasonable price.’²⁷

In recent months, the public has been almost overwhelmed with scientific information regarding the genome, the complexities of gene therapy and stem cell research.²⁸ Yet to come will be efforts to grow certain tissues for grafting, including skin, bladder and cartilage. Reportedly, cultured cells have been used successfully in an experimental setting to treat stroke victims. It is expected that similar cells can be used to treat other disabling brain diseases. Genomics-derived drugs hold the potential to expand greatly the range of treatments achievable with human cells, because of their ability to control the cells as they grow and specialise.²⁹ Even more opportunities for regenerative medicine will be charted when the insights from the clonal experiment with Dolly the sheep are realised, first with a re-set of the genetic clock inside a cell and, subsequently, without the need for egg cells.³⁰

A. *Cases in Point: Achievements or Potential Catastrophes?*

Three recent startling scientific achievements both bring into clear focus and, indeed, test the extent to which — if any — restraints should be imposed upon medical technology.

26 George J Annas, *Standard of Care: The Law of American Bioethics* (1993) at 252–253.

27 *Id* at 216. See generally George P Smith, II, ‘Utility and the Principle of Medical Futility: Safeguarding Autonomy and the Prohibition Against Cruel and Unusual Punishment’ (1996) 12 *J Contemp Health L and Policy* 1; George P Smith, II, ‘Stop, in the Name of Love!’ (1990) 19 *Anglo-American LR* 55.

28 See Caplan, above n11 at 181–193; Michael Kirby, ‘The Human Genome’ in *Through the World’s Eye* (2000) at 41–51; George P Smith, II, ‘Harnessing The Human Genome Through Legislative Constraint’ (1998) 5 *European J of Health L* 53; Symposium, ‘Human Primordial Stem Cells’ (1999) 29 (2) *Hastings Ctr Rpt* 30; Geoffrey Carr, ‘Survey: The Human Genome’ *The Economist* (1 July 2000).

29 William A Haseltine, ‘Genomics: The Path Ahead for Science, Medicine and Society’ (2001) 19 *Brookings R* 20 at 22–23.

30 *Ibid*; see also Chet Fleming, *If We Can Keep a Severed Head Alive ...: Discorporation and US Patent 4,666,425* (1988); George P Smith, II, *Medical-Legal Aspects of Cryonics: Prospects for Immortality* (1983); Robert Bahr, ‘A New Ethical Question: Head Transplants?’ (1977) *Science Digest* (May) 76. See generally George J Annas, ‘The Man on the Moon, Immortality, and Other Millennial Myths: The Prospects and Perils of Human Genetic Engineering’ (2000) 49 *Emory LJ* 753.

(i) *Designing Human Viruses*

The shadowy world of designer pathogens was brought to the forefront when Australian scientists created, accidentally, a virus that kills mice by crippling their immune systems. A startling warning came with this discovery: it may pose as a threat or precursor to deadlier forms of human viruses and new kinds of biological weapons. Since humans have the same immune system gene as mice (interleukin-4) to control immune responses, 'in theory a similar step could create a pathogen deadly to people'.³¹

(ii) *ANDi*

Since 1976, when the first gene-altered animal — a mouse — was created, other successes with fruit flies, rabbits, sheep, goats, cattle, pigs et cetera have been recorded. In October 2000, however, the first altered primate, a rhesus monkey named ANDi, was created. He was made by splicing jellyfish genes into eggs of rhesus monkeys. Although the technique did not work completely, the jellyfish gene can be found throughout ANDi's cells. This process gives some credence to ethical fears scientists may one day use similar techniques to add desirable traits to human embryos thereby heralding an era of designer babies. Yet, it also brings the hope of producing animals with genes that cause Alzheimer's disease, breast cancer, hereditary blindness and other ailments so that, in turn, therapies and vaccines can be tested.³²

(iii) *Cloning Human Embryos*

The British Parliament enacted legislation relaxing the rules limiting research on human embryos under the *Human Fertilisation and Embryology Act 1990* (UK). Taking effect 31 January 2001, the legislation continues the prohibition on creation of babies by cloning, but allows research on stem cells and mandates the destruction of the clones after 14 days of development.³³

Stem cell research involves, inevitably, embryo cloning because physicians want to treat their ill patients with cells from their own bodies. After alteration, the cells would be cloned and returned to the patient in order to replace damaged or dead cells causing illness.³⁴ The process requires the removal of the nucleus of a donor egg and its replacement with a cell from an ill patient. The egg would then be induced to divide and start growing into an embryo. The cloned cells would be identical, genetically, to the patient's and therefore could overcome, theoretically,

31 William J Broad, 'Australians Create a Deadly Mouse Virus' *New York Times* (23 Jan 2001) at A6.

32 Rick Weiss, 'Scientists Create First Genetically Altered Monkey' *Washington Post* (12 Jan 2001) at A1; see also Robert P Lanza, Betsy L Dresser & Philip Damiani, 'Cloning Noah's Ark' (2000) 283 *Scientific American* 84.

33 Emma Ross, 'Britain Legalizes Cloning Human Embryos' *Washington Times* (23 Jan 2001) at A1; Philip Webster & Greg Hurst, 'MPs Give Go Ahead for Embryo Research' *The Times* (20 Dec 2000) at 1.

34 *Ibid.*

problems of transplant rejection.³⁵ In the United States, early stage embryonic stem cells are obtained from either the donated or purchased embryos produced in private laboratories, especially fertility clinics.³⁶

In all three of these new scientific breakthroughs, caution must be taken to exercise — with a spirit of humanism — their capabilities. Misuse surely, in the words of Julius Stone, holds the real potential for ‘cataclysmic’ consequences.³⁷ Yet, the potential for minimising human suffering exceeds — on balance — the fear of the negative. Indeed, it could be argued that failure to pursue the scientific limits of these three achievements would be irresponsible. Both the long and the short term costs and fears (for example, economic, social, ethical) of placing a moratorium on scientific inquiries of this nature do not outweigh the untold medical benefits accruing to society from their pursuit and development. In a word, pursuing these three breakthroughs is reasonable.

4. *Micro Considerations*

The American health care system has been termed, ‘technologically-driven, [and] death-denying’.³⁸ So long as individuals persist in their desire to live as long as possible, the frontiers of medical science will always be expanding.³⁹ While marginal improvements may be recorded at the end stage of life, these improvements may be worthless qualitatively to the patient and, indeed, ‘extraordinarily expensive to society’.⁴⁰ Costs can never be contained until mortality is accepted,⁴¹ and ‘despair and rage at the finitude of human existence’ is dispelled.⁴² Designing a socially acceptable set of normative standards for dispensing health care is the challenge for contemporary society.

A. *Gatekeeping*

The primary gatekeepers to national expenditures for health care are the physicians. It is they who either limit or facilitate not only medical tests, but treatment and consultations as well as initial admissions to various health care institutions.⁴³

35 Mona S Amer, ‘Breaking the Mold: Human Embryo Cloning and its Implications for a Right to Individuality’ (1996) 43 *UCLA LR* 1659; George P Smith, II, ‘Intimations of Immortality: Clones, Cryons and the Law’ (1983) 6 *UNSWLJ* 119; see Rick Weiss, ‘US Fertility Expert Announces Effort to Clone a Human: Consortium Led by Renegade Doctor Says it Will Help Infertile Couples’ *Washington Post* (27 Jan 2001) at A3.

36 See Rick Weiss, ‘Fetal Cell Research Funds Are at Risk: Scientists Fear Curbs Over Abortion’ *Washington Post* (26 Jan 2001) at A3; Rick Weiss, ‘Panel Drafts Ethics Plan for Embryo Cell Studies: Rules Would Guide Federally Funded Research’ *Washington Post* (9 April 1999) at A2.

37 Above n12 at 240.

38 Above n26 at 211.

39 *Id* at 214.

40 *Ibid*.

41 *Id* at 216.

42 Daniel Callahan, *Setting Limits: Medical Goals in an Aging Society* (1987) at 66.

43 Edmund D Pellegrino, ‘Rationing Health Care: The Ethics of Medical Gatekeeping’ (1986) 2 *J Contemp Health L and Policy* 23; ‘The Physician’s Role in Cost Containment’ (1996) 3 *J of Critical Care Nutrition* 40.

The physician assumes one of three roles as a gatekeeper: the de facto function, which sets a responsibility to practise rational medicine or medicine which is beneficial and effective for the patient; negative gatekeeping, under which a form of prepayment system requires the physician to limit the use of health care services; or as a positive gatekeeper, where he or she encourages the use of health care services and facilities for either corporate or personal profit.⁴⁴

B. Allocating and Rationing Health Care

Regardless of which of these three roles are assumed by the gatekeepers, primary issues of allocation and rationing are central to all of them; for health care involves a competition for limited resources and therefore — at one level or other — forces a cost-benefit approach which balances reasonable individual needs against the availability of medical resources.⁴⁵ In the face of ever mounting distribution costs, it is the elderly, in specific, who become major players in the health care drama for which they are cast in alternating roles as victims and as villains.⁴⁶ The health care system helps to prolong their lives, yet at the same time, puts more and more dollars into geriatric spending.⁴⁷ The ethical issue implicit here involves the fair distribution of public resources among the different age groups.⁴⁸

(i) Allocations

Interestingly, in England, the practice of allocating resources based upon age stems from a paternalistic system that gives greater deference to its physicians who are then able to directly influence patient choices.⁴⁹ The allocation of health care resources ‘involves a societal determination of what resources should be devoted to a particular program’.⁵⁰

Perhaps the best examples of age-based allocation schemes are to be found in the experiences of other countries, where cost containment initiatives result in indirect limits on care for the elderly.⁵¹ The cost-benefit approach to the distribution of health care resources is impractical — from an ethical viewpoint — because it seeks to reduce (or convert) all health benefits to dollar amounts, thereby seeking very awkwardly to convert quality of life benefits into unyielding economic terms.⁵²

44 Ibid; see also Edmund D Pellegrino, ‘Managed Care at the Bedside: How Do We Look in the Moral Mirror?’ (1997) 7 *Kennedy Inst Ethics J* 321; Edmund D Pellegrino, ‘Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician–Patient Relationship’ (1994) 10 *J Contemp Health L and Policy* 47; see generally Robert B Pippin, ‘Medical Practice and Social Authority’ in James L Nelson & Hilde L Nelson (eds), *Meaning and Medicine: A Reader in the Philosophy of Health Care* (1999).

45 See Daniel Callahan, ‘What is a Reasonable Demand on Health Care Resources? Designing a Basic Package of Benefits’ (1992) 8 *J Contemp Health L and Policy* 1.

46 See Harry R Moody, *Ethics in an Aging Society* (1992) at 4.

47 Ibid.

48 Id at 5; see George P Smith, II, *Legal and Healthcare Ethics for the Elderly* (1996) at 25–34.

49 Above n46 at 197.

50 George P Smith, II, ‘Our Hearts Were Once Young and Gay: Health Care Rationing and the Elderly’ (1996) 8 *Fla JL & Pub Policy* 1 at 9.

51 Above n46 at 205.

52 John McKie, Helga Kuhse, Jeff Richardson & Peter Singer, ‘Allocating Healthcare by QALYs: The Relevance of Age’ (1996) 5 *Camb Q Healthcare Ethics* 534.

One method proposed as a solution to this inequality of the cost-benefit analysis seeks to evaluate the quality-adjusted life years (QALYs) produced for each available health care dollar.⁵³ The goal of this resource allocation strategy, then, is to maximise the most QALYs for each available health care dollar.⁵⁴ There is a central weakness to this method, however, because considering the limited remaining life years of the elderly — individually and as a group — and calculating their QALYs are highly problematic. Thus, for example, a group of elderly individuals needing a surgical procedure will not fare as well using the QALY approach as a younger group of patients — this being rather obvious inasmuch as the older patients in the group have fewer remaining years to live.

(ii) *Rationing*

Health care rationing is the fair distribution of limited resources by limiting the availability of various programs and services.⁵⁵ A concern with rationing, the planned distribution of limited resources, is devising a system that is fair and equitable.⁵⁶ In the current American health care system, the ability-to-pay is used as an implicit rationing device; yet, a lack of consensus in values and norms prevents a specific method from being developed to achieve the ends of rationing health care services.⁵⁷ ‘Thus, the debate is no longer whether health care should be rationed, but rather, how to ration it equitably.’⁵⁸

Health care decisions, in the control of third-party payers, have distorted the ability to make real choices.⁵⁹ Cost containment issues in geriatric health care have also changed the role of physicians, and forced them, as seen, to become reluctant medical gatekeepers.⁶⁰ Inherent in health care decisions is the conflict between saving costs and obtaining quality health care.⁶¹ In essence, ‘rationing has come to represent discrimination in access to health care services on the basis of socioeconomic status.’⁶²

53 Ibid.

54 See *id* at 535 (‘If health program A has the potential for producing more QALYs than health program B for a given cost, then program A should be a higher priority for funding’); above n48 at 30–32.

55 See above n50 at 10–11 relating rationing to health care needs.

56 Dorothy C Rasinski-Gregory & Miriam Piven Cotler, ‘The Elderly and Health Care Reform: Needs, Concerns, Responsibilities and Obligations’ (1993) 21 *West St ULR* 65 at 83.

57 See *id* at 83–86, noting the possibility of many different criteria such as age, disease, and entitlement.

58 Above n50 at 17.

59 Above n46 at 39.

60 Above n43; Edmund D Pellegrino, ‘The Commodification of Medical and Health Care: The Moral Consequences of a Paradigm Shift from a Professional to a Market Ethic’ (1999) 24 *J of Med & Philosophy* 243.

61 See Joanne Lynn, ‘Ethical Issues: Equitable Distribution and Decision Making’ in Marshall Kapp, Harvey Pies & A Edward Doudera (eds), *Legal and Ethical Aspects of Health Care for the Elderly* (1985); see also Edmund D Pellegrino, ‘Metaphors, Managed Care and Morality’ (1995) 3 *J of Critical Care Nutrition* 40.

62 Above n50 at 11.

Rationing must be viewed as more than limiting care, for it is a means of providing care where resources are managed and preserved.⁶³ Rationing is also access control, which is dependent on the medical good, the patient's values, and the needs of society itself.⁶⁴ Here, justice involves a constant balancing between the good of the individual and the needs and good of society.⁶⁵

In the 1980s, several ethicists became noted proponents in favour of rationing resources based on age. Callahan boldly proposed a working model based on distributive justice and an individual's life span, where chronological age became the dispositive factor in cutting off health care resources.⁶⁶ Others have also suggested similar denials of treatment based upon an individual's age.⁶⁷

The moral and social costs of age-based rationing are indisputably very high, as 'the elderly [would] receive less than their economic due as a return on their prior investment to society'.⁶⁸ Indeed, the harshest criticism against rationing is seen in the misperception that health care will be withheld or withdrawn based solely on economic decisions.⁶⁹

Rationing health care to the elderly is based traditionally upon a cost-benefit analysis that views the elderly as poor investments per health care dollar, or a use of scarce resources with limited returns.⁷⁰ The basic argument advanced here is that other segments of the population have more of a potential return on the investment of health care dollars than the elderly.⁷¹ Rationing does not mean necessarily the withholding of *all* medical care. Instead, expensive treatments should be abandoned when the chances of positive, rehabilitative results are minimal.⁷² Thus, the primary negative for age-based rationing is the demeaning notion of placing a monetary value on an elderly person's life.⁷³

63 See David C Thomasma, 'The Ethical Challenge of Providing Healthcare for the Elderly' (1995) 4 *Camb Q Healthcare Ethics* 148 at 152.

64 See *id* at 155, noting that the physician and patient must negotiate the good to be accomplished.

65 *Ibid*.

66 Above n42 at 49; see also Daniel Callahan, 'On Turning 70: Will I Practice What I Preach?' (2000) 127 (15) *Commonweal* at 10, re-arguing that expensive, short-term, life-extending technological rescues from impending death should be resisted steadfastly by the elderly (for example, from age 65 to the early 80s) *but only* if and when the point arises in America where the health-care maintenance costs of the elderly become so insupportable that they are 'depriving younger people of what they need to live decent lives and to have a chance of becoming old'.

67 Robert M Veatch, 'Justice and the Economics of Terminal Illness' (1988) 18 *Hastings Ctr Rep* 34 at 39, suggesting that the old have already consumed more than their fair share of resources; see also Henry J Aaron & William B Schwartz, *The Painful Prescription: Rationing Hospital Care* (1984) at 34-37, documenting the withholding of kidney dialysis treatment based on age.

68 Above n56 at 90.

69 Above n63 at 149.

70 Andrew H Smith & John Rother, 'Older Americans and the Rationing of Health Care' (1992) 140 *U Pa LR* 1847 at 1849-1850.

71 *Id* at 1853.

72 *Id* at 1850; see also George P Smith, II, 'Triage: Endgame Realities' *J Contemp Health L and Policy* (1986) 143 at 149, suggesting that love and humaneness serve as guides to determine when treatment cease — this, tested against the ability of the patient to engage in or sustain human relationships.

73 See above n50 at 14.

Chronological age alone, as the determinative factor, fails as a practical approach in making health care decisions because of the great 'divergence between theory and practice'.⁷⁴ Instead, other variables, such as quality of life and health factors, are as equally important in determining treatment for the elderly.⁷⁵ The utilitarian view of health care advocates balancing many different factors, such as public and private benefits, predicted cost savings, risks involved and necessary trade-offs.⁷⁶ In contrast, others argue a functional approach to rationing where the functional status of the person takes precedence over any utilitarian balancing.⁷⁷ No doubt, the best gatekeeping ethic is to be found in the inherent physician-patient relationship — a relationship based on mutual trust and access to health care information, which then allows treatment to be consistent with a patient's preferences or recovery potential.⁷⁸ The major factor in addressing health care rationing should not be age. Rather, the course of a patient's treatment should be dependent solely upon his or her individual medical condition,⁷⁹ and shaped always by the goal of humane, loving care which reduces human suffering, enhances the common good, as well as safeguards the dignity of the human spirit, especially in end-game situations.⁸⁰

C. *Generational Justice*

The concept of intergenerational equity arises from the association between the increased number of persons over 65 years, the probability that they are frequently using health care resources, and the resultant increase in health care costs.⁸¹ The government is not able to bear, without restraint, the growing social and economic health care costs associated with the elderly. In America, during the presidency of Ronald Reagan, federal funding failed to keep pace with demand, as the demand for resources far out-distanced the available supply.⁸² Every dollar given to the program for the elderly meant one less dollar for other groups. Addressable economic issues included then, as now, the proper delivery of care, the allocation of resources, effective and affordable methods of insurance, and defining research priorities.⁸³

The fastest growing population in the United States and worldwide are people over the age of 65.⁸⁴ 'A corresponding shrinkage occurs in the population under

74 Above n46 at 190.

75 See id at 189.

76 See Tom L. Beauchamp & James F Childress, *Principles of Biomedical Ethics* (4th ed. 1994) at 47-55.

77 Above n63 at 157, explaining that a full functioning human person — 'status one' — has all treatment 'open for discussion', whereas an individual suffering from endstage Alzheimer's disease — 'status four' — has 'only methods of supportive care and ... nutrition ... open for discussion'.

78 Above n56 at 91.

79 See above n70 at 1856.

80 See Smith, II, 'Stop, in the Name of Love!', above n27 at 60, 70-71.

81 See above n56 at 93.

82 Lawrence A Frolik & Alison P Barnes, 'An Aging Population: A Challenge to the Law' (1991) 42 *Hastings LJ* 683 at 707-709.

83 Above n42 at 117.

84 See above n63 at 148-149.

65 years-of-age who will have to bear the burdens of providing for the prior and the future generations'.⁸⁵ Furthermore, the elderly are disproportionate consumers of health care as hospitalisation of elderly persons on the average costs three times more per health care dollar than those under 65 years of age.⁸⁶

There is some merit to the argument, however, that the elderly must be compensated for their work earlier in life and not be required to make additional health care sacrifices.⁸⁷ Due to their advanced years, the elderly earn some degree of public sympathy and respect because of what they have accomplished before approaching the end of their lives.⁸⁸ In coming to this end, they have discharged already many of the obligations that society has required and should not bear a disproportionate burden in their later years.⁸⁹

Arguably, there is a shared inter-generational duty between both the elderly and those who are younger. Assurances against neglect and abuse come from the moral obligations and relationships that the young have with the elderly.⁹⁰ At the same time, the elderly are stewards of a world they helped fashion and their purpose should be to aid the young and future generations to come.⁹¹ Therefore, the proper role for all societal groups should recognise a life cycle where the elderly have come before the young and made life easier for those who follow, while the young have the burden of supporting the elderly when they are unable to take care of themselves. The extent of that burden remains the open and truly vexatious question of this century.

5. *Deliberative Democracy*

As advances in medicine and technology continue and, as a consequence of this, social, economic and legal conflicts arise, a central concern becomes whether there is a proper foundation upon which informed debate and decision-making can proceed. Deliberative democracy has been popularised and advanced as the cornerstone upon which informed decision-making can occur.⁹²

As a concept, deliberative democracy seeks to expand the number of forums where citizen participation can take place — with mutually respectful decision-making being the aspirational goal.⁹³ The best example of this conception in action

85 *Id* at 148.

86 *Ibid*.

87 See *id* at 156, noting that the elderly are responsible for having built 'the roads and bridges, symphonies, and schools we now enjoy'.

88 Above n82 at 713.

89 See above n63 at 156, quoting, 'While the elderly may gobble up inordinate relative amounts of healthcare dollars, while doing so, they are not using other resources of society — general resources use equalises out in the end'.

90 See above n42 at 83, noting familial relationships and governmental such as Social Security and Medicare.

91 *Id* at 82.

92 See Amy Gutmann & Dennis Thompson, 'Deliberating About Bioethics' (1997) 27 *Hastings Cntr Rep* (3) at 38.

93 *Id* at 40.

is to be seen in Oregon's efforts in the early 1990s to set priorities for publicly funded health care under Medicare.⁹⁴ Initially determined by the Oregon Health Services Commission, the list of priorities was shaped by what was viewed as harsh utilitarian cost-benefit calculations.⁹⁵ As a response to heavy public criticism of the process, a comprehensive plan was developed which, in turn, allowed the Commission to meet widely with the community through open meetings. Further deliberations were undertaken by the Commission and a revised list was drawn up, promulgated and approved.⁹⁶

While deliberative democracy is viewed in theory as an attractive complement to the legislative process, the major drawback to its effective implementation is a simple realisation: namely, that the average, ordinary American (or, for that matter, world citizen) is not sufficiently sophisticated or informed to enter into meaningful dialogue on the limits and uses of the new Age of Medical Science. All too often, logic is put on 'hold', while unfounded fear and emotional feelings shape the debate.⁹⁷ Similarly, economic realities are repeatedly ignored or postponed until a time when their forced implementation causes more discord and havoc than would have occurred if they had been considered as a first order priority.⁹⁸

Even with an ethic of openness within a deliberative democracy, the insuperable obstacle to an informed and constructive debate is the inability of the public to understand the language of the scientists, that is, the language of statistics.⁹⁹ Yet polls are a popular way to gauge public opinion — informed or uninformed, as the case may be. Often they are used as barometers by legislators and judges when trying to shape new responsive laws and set new public policies. One such survey is of particular relevance.

In 1996, Environics, a Canadian polling firm, contacted 25,000 people in 30 countries and asked their response to two questions: whether they strongly favoured, somewhat favoured, strongly opposed or somewhat opposed applying biotechnology to develop medicine and treatments for human diseases; and, if animals were cloned to produce new biotechnology medicines to fight human diseases, would they strongly favour, favour somewhat, strongly oppose or

94 The Oregon health care rationing plan was crafted on the basis of what medical problems would be covered rather than who was to be covered. W John Thomas, 'The Oregon Medicaid Proposal: Ethical Paralysis, Tragic Democracy, and The Fate of a Utilitarian Health Care Program' (1993) 72 *Or LR* at 47.

95 *Id* at 153.

96 Above n92 at 41; see also Eric L Robinson, 'Special Project: The Oregon Basic Health Services Act: A Model for State Reform?' (1992) 45 *Vanderbilt LR* 977, noting that the use of community values enhances the effectiveness of medical services.

97 George P Smith, II, 'Judicial Decision making in The Age of Biotechnology' (1999) 13 *Notre Dame JL Ethics and Pub Policy* 93 at 93, 103.

98 See Stephen F Williams, 'Limits to Economics as a Norm for Judicial Decisions' (1997) 21 *Harv JL and Pub Policy* 39; see generally Richard A Posner, *Economic Analysis of the Law* (5th ed, 1998).

99 See Robert Schwartz, 'Genetic Knowledge: Some Legal and Ethical Questions' in David C Thomasma & Thomasine Kushner (eds), *Birth to Death: Science and Bioethics* (1996) at 25; see also Jane Gregory & Steve Miller, *Science in Public Communication. Culture and Credibility* (1998) at 249; Albert R Jonsen, *The Birth of Bioethics* (1998) at 367–371.

somewhat oppose the use of biotechnology? To the first question, 78 per cent of the respondents in the Australian survey answered either strongly in favour or somewhat in favour of pursuing biotechnology to advance medical science — with 90 per cent of the Americans answering similarly. In response to the second question, only 38 per cent of the Australians declared themselves as strongly or somewhat in favour of cloning animals for developing new biotechnology medicines — while 47 per cent of the Americans surveyed expressed similar views.¹⁰⁰

6. Conclusion

Richard Epstein has concluded that 'simple and compact' common law rules are a far more effective tool for providing health care than endless sets of legislative and judicial innovations.¹⁰¹ And at the heart of the common law lies the normative standard of reasonableness, which is forever tested by applying a deceptively simple balancing test — a test that measures the gravity of the harm of a decision against the social utility or values of maintaining the status quo under challenge.¹⁰²

In the contest of the distribution of health sciences, this approach forces an evaluation of the balance of competing individual interests or social values.¹⁰³ Accordingly, the value and cost to society of expending scarce health care resources, for example, to maintain individuals who have a futile medical prognosis, is balanced against the economic utility of providing care to those whose health care can be restored or rehabilitated.¹⁰⁴ Age, as well, should not be seen as the determinative factor in the health care services balancing test. Rather, a patient's condition, informed or negotiated consent to treatment, and primary physician's professional judgment as to the need for the commencement or cessation of medical services should be controlling.¹⁰⁵ What is the most efficacious and humane treatment and in a patient's best interests — while varying from situation to situation — is nonetheless a medical judgment.¹⁰⁶ When that judgment to withdraw or withhold care may be called into question by a patient's family, for example, the preferred avenue for resolving disagreement should

100 Dita Smith, 'What on Earth?' *Washington Post* (20 Jan 2001) at A21; see generally Bruce Alberts, 'Biomedical Research in the Next Century' in C Everett Koop, Clarence E Pearson & M Roy Schwarz (eds), *Critical Issues in Global Health* (2001) at 287.

101 Richard A Epstein, *Mortal Peril: Our Inalienable Right to Health Care?* (1997) at 23.

102 See *Restatement, Second, Torts* (1977) §822.

103 Patrick M McFadden, 'The Balancing Test' (1988) 29 *Boston College LR* 585 at 585, 601.

104 See Smith, II, 'Utility and The Principles of Medical Futility', above n27; George P Smith, II, 'Re-thinking Euthanasia and Death with Dignity: A Transnational Challenge' (1990) 12 *Adel LR* 480; see also Michael D Kirby, 'Bioethical Decisions and Opportunity Costs' (1986) 2 *J Contemp Health L and Policy* 7; see generally Smith, II, above n72.

105 Negotiated consent supports 'shared decision making' — although not full equality — among patient, family, surrogate health care decision-maker and physician; Smith, II, above n48 at 48; see also Harry R Moody, 'From Informed Consent to Negotiated Consent' (1988) 28 *The Gerontologist* (Supplementary Issue) 64.

106 Smith, II, above n48 at 75.

always be resort to a hospital ethics committee.¹⁰⁷ Judicial intervention should only be sought when all else fails.

Restraining scientific inquiry should be limited only to action seen as unreasonable. Accordingly, an undertaking would be regarded as unreasonable when the long and short term costs of its effects would outweigh the enduring benefits that would derive from its study and implementation. Viewed as being not only an aid to the tragedy of infertility in family planning, but as a tool for improving the health of a nation's citizens, vital scientific research must continue in the new reproductive technologies and in efforts to engineer man's genetic weaknesses out of the line of inheritance. Healthier and genetically sound individuals have a much better opportunity for pursuing and achieving the 'good life' — and, in turn, they make a significant contribution to society's greater well being.

'If democracy is to be more than a myth and a shibboleth in the age of mature science and technology',¹⁰⁸ a new thoughtful and questioning attitude must be developed — one that, while not viewing scientific discovery with deference and uncertainty, nonetheless refuses to allow scientific and technological directions to be set without participation and question.¹⁰⁹ If moral ordering is to be of significance and value in medical-legal decision-making in the 21st century, a practical situation ethic — with universality, or worldwide acceptance, as an underpinning — must be observed. This ethic must accept genetic enhancement as valid a goal as the reasonable and efficient delivery of humane and technologically appropriate care for the sick.¹¹⁰

Hopefully, in the final analysis, the law will be seen as a new 'culture' capable of setting and translating standards of normative conduct for this new Age of Biotechnology which are both practical *and* understandable by the citizenry. Ultimately, '[i]t is for our society to decide whether there is an alternative or whether the dilemmas posed by modern science and technology ... are just too painful, technical, complicated, sensitive and controversial for our institutions of government.'¹¹¹

107 George P Smith, II, 'The Ethics of Ethics Committees' (1990) 6 *J Contemp Health L and Policy* 157.

108 Michael D Kirby, *Reform the Law: Essays on the Renewal of the Australian Legal System* (1983) at 238.

109 *Ibid*; see generally, George P Smith, II, *Bioethics and the Law: Medical, Socio-Legal and Philosophical Directions for a Brave New World* (1993); Leon R Kass, *Toward a More Natural Science: Biology and Human Affairs* (1985).

110 See generally George P Smith, II, Monograph, *Genetic Enhancement or Eugenic Improvement: Controlling the Brave New World* (1999).

111 Above n108 at 238–239; see also Gregory & Miller, above n99 at 19–51; see generally George P Smith, II, Monograph, *Bioethics and the Administration of Justice* (1998); Zelman Cowen, *Reflections on Medicine, Biotechnology and the Law* (1986); Yvonne Cripps, *Controlling Technology: Genetic Engineering and the Law* (1980).