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UNIVERSITY OF GUELPH

GUELPH, ONTARIO, CANADA

WORLD CONFERENCE ON ETHICAL CHOICES IN THE AGE OF PERVASIVE TECHNOLOGY

26 OCTOBER 1989

TECHNOLOGY, ETHICS AND THE ECONOMIC PROBLEM

The Hon Justice Michael Kirby CMG*

THE DISMAL SCIENCE AND ETHICAL CHOICES

Until quite recently the discussion of the economics of ethical choices received little attention. If the topic was mentioned at all, it was usually placed at the end of a conference agenda. Now, increasingly, it is coming to the fore. The impetus for this new attention to the economics of ethical decision-making is technology.

Technology presents marvellous opportunities to the community and to individuals. It may save lives. It may reduce pain and suffering. It may improve the quality of life. But the use of technology necessarily involves decisions of resource allocation. Such decisions must be made in the universal context of the economic problem. It is

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so in the richest societies. The choices may be even more painful in the poorer societies. But choices must be made all the time. Those choices will affect the continuance or termination of human life, the relief or prolongation of human suffering and the quality of life of those concerned.

The decisions must typically be made both at a macro and micro level. At the macro level, politicians and their bureaucratic advisers must decide upon resource allocation, eg between the health budget, defence, education and law and order. Health administrators, nowadays scrutinizing their computer printouts to see unusual prescription patterns amongst medical practitioners, must decide on resource allocation at the state, district and hospital levels. Their decisions will, in turn, have ripple effects which inescapably impact individual decisions. At the micro level the triage sister in the emergency ward and the medical practitioner at the local surgery, daily confront a myriad of decisions which mix medicine, ethics and economics. It is in this sense that the physician has been called the "gatekeeper". He or she makes critical decisions of great individual impact. In aggregate, such decisions have enormous economic importance.²

In the good old days, before these hard realities pressed upon us, we tended to think (or at least say) that every individual life was infinitely important and every possible reasonably available resource known to science should be devoted to its preservation and well being.

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Nowadays the rude realization of the economic problem requires greater realism from us. We must face the facts that resources are necessarily limited and choices as to their allocation are virtually limitless. Accordingly, decisions must be made. As such decisions concern technology, they affect life and its quality.

The articulation of these truisms has appeared with increasing force in recent medical and other scientific literature. The catalyst for realism is expensive technology and the choices which its availability forces upon decision-makers at every level. Professor Albert Jonsen, Professor of Ethics in Medicine at the University of California at San Francisco, expressed the problem thus:

"Many of the technologies under assessment relieve illness or pain or disability, but do not directly save life, do not rescue people from imminent death. Those technologies that do stave off death and sustain life pose a particularly daunting problem to the assessor; they interpose into the miniature felicific calculus a barrier difficult to climb, a chasm difficult to leap: namely the imperative to rescue endangered life.

Major organ transplantation and implantation are the most striking examples of these technologies. Our working groups were able to calculate the extent of possible use, the possible efficacy and the costs of these technologies. The artificial heart, for example, might annually bring four years of extended life to some 25,000 persons at a cost of some \$10,000 per life saved. Allowing these persons to die without any treatment for cardio myopathy would be much less costly, since the alternative for them is not a lifetime of expensive chronic care, but death. Also, the burden of paying for these transplants might eventually pinch the nation's health resources budget, depriving many of less dramatic but nonetheless life-enhancing forms of care.

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Should we encourage the development of the artificial heart? Of course we must, it is said, because it rescues the doomed from certain death. And those doomed to death are certainly quite visible individuals - Dr Barney Clark, William Schroeder, Baby James Fisk and Baby Jessie, my son, your wife, the nice man next door - rather than the invisible multitudes who may die of exposure to toxic chemicals, cigarette smoke or radiation or those deprived of immunization or adequate nutrition. We reach a conclusion contrary to the utilitarian principle: we benefit a few at cost to many."³

The fact that it is new technology which has brought economics into ethical decision-making at a most acute level is demonstrated by many writers. Whether the health care system is modelled on that of the United Kingdom, the United States, Canada or the hybrid system of Australia, expenditures for health care are rising rapidly. Advances in medical technology account for a large part of these increases. Professor George P Smith has made this point:

"While much of the rise in [health care] costs can be attributed to advances in medical technology, certain forms of life-saving treatment are acknowledged as being focal points these increased health costs. of More specifically, approximately \$30,000 a year is spectrically, approximately \$30,000 a year is spent on each patient receiving haemodialysis treatment - with the 1981 figure showing more than 50,000 patients receiving this particular treatment. The cost of each coronary artery bypass operation is between \$10,000-\$20,000 and these surgical interventions account for 1% of the total annual health care budget - with this 1% point translating into \$2 billion a year. Two other examples of high budget items in modern medical technology are to be found in the wide use of computerised tomography or CT scanners and intensive care units - particularly in neonatal. Sophisticated neonatal care is not. only costly, but scarce, with demand often exceeding the supply of beds, equipment and personnel. What is seen, then, is that

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physicians and hospitals are often times being forced to choose which newborns receive intensive care and which ones do not. Decisions of this nature - in turn - involve a plethora of medical, moral, legal and economic problems with the central-most issue being how to best distribute scarce neonatal intensive care resources."4

The recognition of the economic and ethical choices forced upon politicians, bureaucrats, health administrators and individual health workers is not entirely new. Every generation had its novel developments for which, at the start at least, demand necessarily outstripped supply. But it is the variety, utility and cost of the latest medical technology that makes the choices most urgent. Professor Rosemary Donley has described the realization of this in the following terms contrasting earlier, less technological times:

"[P]atients died during therapeutic heroics. Lack of science and the virulence of disease were fatal combinations. Today, the level of science requires not a painful prescription but rather an informed judgment about the merits, @ efficacy, benefits and desirability of available and experimental treatments. The power of our knowledge has advanced to the point where the treatment might work. [Accordingly], modern clinicians balance not only the cost to the client (and the system) but also the risk to the patient (and the system). Clinicians must make decisions based on the probability that treatment might restore life and health, albeit compromised. We have given clients new, more painful and more costly ways to live and die. Justice mandates that decisions about access to health care should consider benefit as well as cost.5

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THE CASE OF DEREK SAGE

To bring these generalities down to a practical level is useful. It illustrates what I am talking about. It will help to focus the necessity for ethical choices and the procedures and on the criteria by which (as societies and individuals) we make those choices.

Take, first, the case of Derek Sage. Early in 1983, Sage, then aged 42, came under the care of the renal unit Mr at the Churchill Hospital, Oxford, England. Mr Sage had a history of psychiatric illness, hypertension and impaired renal function. His right kidney did not function and his left kidney was defective. He lived at Simon House, an Oxford hotel for single homeless men. By March 1984 the functioning of his kidneys had become so poor that he required dialysis. However, immediately after this treatment began, his mental state deteriorated. He spent a period of months in a psychiatric hospital being brought regularly to Renal Unit for dialysis. His behaviour become the 'increasingly disruptive' when he visited the unit. Α previously suspected brain tumour was re-explored and it was found that there were extensive areas of cerebral damage. He became demented. His mental age was put at about 3 years. He did not respond to simple questions. At times he was violent, generally uncooperative, dirty, incontinent of urine and faeces, unable to take medication reliably and he could not adhere to a prescribed diet. He exposed himself and masturbated whilst being examined. A great part of his life was spent under sedation, particularly when he was being dialysed. His blood pressure was not properly controlled.⁶

The renal unit staff came slowly but surely to the painful conclusion that the treatment by dialysis was a "failure". The dialysis sessions were proving a torment to both the patient and medical staff and the unit's capacity to deal with other patients.⁷

When Mr Sage arrived at the unit for routine dialysis on 28 December 1984 the nurses on duty told the consultant in charge that, in their view, the continuation of his treatment was 'not in the patient's best interest'. The consultant, it seems, expected 'fierce opposition' to any decision to end the treatment. But the decision was made. And it was made without consulting the hostel staff or the general practitioner who had been treating Mr Sage. These 'friends' of Mr Sage learned of the decision on 31 December 1984. They were shocked and angry. They asserted that there was a 'reasonable quality of life' which could be enjoyed by Mr Sage. They begged the consultant to change his mind. He declined to do so. Opportunity for review of the decision were offered to the local medical authority. However, the decision had to be made promptly as, without dialysis, the patient would soon die.

It was at this stage that the director of the hostel for homeless men in which Mr Sage had spent his life approached the President of the British Kidney Patients' Association. An appeal was made, not to the courts

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(as would probably have occurred in the United States of America) but to the High Court of public opinion. Items began to appear in the media. The British Kidney Patients' Association took this unlikely, and seemingly unattractive, patient as a symbol and as an example of the scarce resources available in Britain for the treatment of patients requiring dialysis. A Labour member of Parliament called for an independent inquiry into the issue of allowing some kidney patients to die because doctors believed that it was 'not worth keeping them alive'." The Oxfordshire District Health Authority defended the decision. It asserted that the decision in Mr Sage's case had been taken 'purely on medical grounds'. It dismissed the claim that his treatment had been cut off after two years because he was 'dirty and difficult'. It also dismissed the suggestion that the County was practising 'passive euthanasia'. However, a spokesman did concede, in a rather British way:

"He will not take his tablets to keep his blood pressure down. Possibly if he had come from a better background and stable home he would still be treated."⁹

It was pointed out that far from being unduly parsimonious in the provision of dialysis, Oxford's provision for kidney dialysis was actually higher than the national average in Britain. Furthermore, the Oxford authority had a policy of continuing to treat patients who had a high risk of dying.

The British Kidney Patients Association was unconvinced. It offered to pay the £400 a week

necessary for dialysis to keep Mr Sage alive. The President of the Association declared:

"You cannot say this man's life is more valuable or worthier than another man's life. Can you imagine what this terrible case must mean to dyalysis (sic) patients?"¹⁰

Springing to the defence of the Government, the Under-Secretary of State for Health, Mr John Patten told the House of Commons that the National Health Service in England provided places for 33 people in a million to have dialysis compared with only 22 in a million five years earlier. The Government intended, he said, to increase the provision to 40 places in a million by 1987. However, even at this figure the British level was amongst the lower in Europe. In the United States nearly 90 places in a million were provided. Typical figures for other parts of Europe were Belgium 61, Spain 61, West Germany 56, Austria 54, Norway 54, The Netherlands 46, France 44.

THE CASE OF MCNAIR-WILSON

Now, I ask you to contrast the case of Mr Sage with the case of Michael McNair-Wilson. He is a man aged 54 years who has been the Conservative member of the United Kingdom Parliament for Newbury, not far from Oxford, since 1974. On 8 November 1984, Mr McNair-Wilson made a moving speech to the House of Commons. Amongst other things, he said:

"Since last January, I have been the victim of a rare kidney disease. Without kidney dialysis, I would be a dead man. The NHS met my need for treatment without requiring me to show that I

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had funds to pay for it. It operated on supply and need, not supply and demand. That will always remain true of the NHS. That is why it is such a precious asset to us all."¹¹

The contrast between these two cases could not be more stark. But it merely illustrates the position which exists in overall statistics, by reference to two individual cases. I would not want you to think that Mr Sage was alone in his predicament. The British Kidney Patients' Association maintains that between 2,000 and 3,000 people a year die in the United Kingdom from renal failure and the Association asserts that many of these deaths are unnecessary. The facility for dialysis (not to say renal transplantation) varies greatly from one area of the country to another. Of course, the older you are, the more complications you may have and the less, it seems, is the chance of getting treatment by dialysis. The London Times made an important point, aggregating the experience of Mr Sage in an editorial titled, provocatively, "Prolonging Low Life".¹²

"It would be a mistake to think of the case of Mr Derek Sage, the kidney dialysis patient, as unique. He is unusual only because his treatment was stopped after it had been (sic) begun and because someone else has been found to start it up again. Every year in Britain several hundred kidney patients die without ever being offered treatment even though they could perfectly well be saved in the present state of the medical art, and would be saved in almost any other country in Europe or North America. But usually doctors make a long face and explain to the patients that unfortunately their case is not suitable for dialysis or transplant. They seldom add ... that the patient's unsuitability may reside principally in the intractable system of having passed his 45th birthday."¹³

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The inexorable calendar, and the passing of the years, it seems, is the criterion (or at least one of the criteria) for the availability of this scarce technology in England. Is this a correct principle? Is it an acceptable approach to the application to the business of life and death of the fundamental economic problem: the allocation of scarce resources? The students of economics learn of the "economic problem" in their first lecture. But the community tarries before acknowledging the application of the economic problem to matters so intangible as justice or so essential and personal as life and death. Yet apply it does. And never more so than in our generation.

In the United States, studies have been conducted on the distributional standard for the provision of scarce medical technology, such as dialysis.

The haemodialysis programme of Seattle, studied 87 such centres around the United States. It did so in order to develop a set of criteria for allowing patients to be admitted to their programmes. In the words of Professor Smith:

"The dialysis candidate profile that emerged found the following criteria to be used always in the section and admissions process: medical suitability (good prognosis with dialysis); absence of other disabling disease; intelligence (as related to understanding treatment); likelihood of vocational rehabilitation; age; primacy of application for available vacancy in the haemodialysis age; rehabilitation; programme; and a positive psychiatric evaluation (re acceptance of the kidney disease and goals of the actual treatment).

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The following conditions were judged as excluding selection of a patient for participation in the programme: mental deficiency; poor family environment; criminal record; indigency; poor employment record; lack of transportation; and lack of State residency.¹¹⁴

When the case of Derek Sage is remembered, poor man he failed on virtually every one of the excluding criteria revealed by the Artificial Kidney Center in Washington State. In other words, although in the United States, by Act of Congress, there is a far greater availability of dialysis, Mr Sage may not have done much better there than initially he did in Britain with its much vaunted "free" public health system.

Smith comments on the lesson to be derived from the dialysis case for the general problem of allocating scarce resources to the acquisition and provision of new medical technology:

"Fault may be found with one or more of these [disqualifying] factors used in selection [for dialysis]. But, absent a unifying philosophy of medicine which defines with precision its goals for achievement, acknowledges whether such achievement is possible and determines whether it reflects a desirable goal of contemporary human culture, and develops rational guidelines for making necessary critical choices, medicine will not be successful. Today there is a recognition that an admirable goal of a national health policy is quality health care at an affordable cost. Cost containment thus has become a major force of wide significance and application in all levels of health-care decision-making. There is little disputation of the fact that resources are scarce relative to wants and that they have alternative uses; and furthermore the differences in individual wants mean an assignment of different values to those wants. The basic dilemma, then, is where to determine a line to compromise between competing interest groups."15

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OTHER CASES

There are many other cases dealt with in the literature which call for ethical choices by reference to new medical technologies.

CT scanners - The provision of CT scanners has often been mentioned. These were first introduced in about When initially introduced there was a serious 1979. shortage in the facility for CT scanners. There was also a shortage in the places that could be made available for use of the equipment with its remarkable diagnostic abilities. The only answer then was to ration the accessibility of this new medical tool. In theory, the early CT scanners, at least in Australia, were provided to the major teaching hospitals only. It was asserted that they would be available there to provide a service to the district. In practice, the rationing which took place frequently depended upon whether the patient's doctor was attached to the hospital, fortunate enough to have the CT scanner. It is one thing for government health administrators to lay down broad equitable principles. It is another for people on the spot, with control of access to the facility, to ignore their institutional loyalties and time-honoured ways of doing things. Yet access to the CT scanner can be extremely important as was recognised from the very earliest days of its availability.

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Opinions differ on the influence of CT on patient management in oncology.¹⁶ However, reported studies indicate that CT directly alters clinical decisions in between 14 and 30% of patients.

Nuclear magnetic resonance - The further development of nuclear magnetic resonance (NMR) provides for even more sensitive examinations than CT. It is particularly useful in the diagnosis of benign tumours at the back of the brain. It can help in differential diagnosis, taking the technology one step beyond CT. Initially only three NMR units were recommended for installation in Australia in teaching hospitals in Brisbane, Sydney and Perth. The total cost of these units, recommended by the Australian National Health Technology Advisory Council, was to be \$9.9 million. However, the Australian Federal Cabinet decided not to fund the purchase immediately. This decision was made on total macro-economic grounds by those who have to choose between the ultimate resource allocations of the the elected leaders.¹⁷ A further decision nation: was made that no medical benefits should be provided for the costs of any private NMR that any enterprising medical entrepreneur should decide to introduce to Australia. The Royal Australasian College of Radiologists condemned these decisions as "unconscionable". It would result, so the College said, in the Australian public "not obtaining access to-

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the most effective diagnostic services". As a result, patients were being flown to the United States for NMR investigation.¹⁸

In vitro fertilization - The cost of health care for infertile couples has also engaged a great deal of attention in Australia where early advances were made in the techniques of in vitro fertilization. Of the many debates that surround this technological advance, one of the most muted has been concerned with the costs of the procedure. Because only approximately 6% of submit infertile couples who to the treatment ultimately succeed in securing a pregnancy carried to full term, questions are raised as to whether IVF is a good investment for the scarce medical dollar. Insofar as it is funded (or partly funded) by Medicare benefits derived from the public purse, critics suggest much better ways to spend the same dollars. These include public education in venereal and other diseases that can reduce fertility, reduction of abortion by proper support for women prepared to continue with the pregnancy and greater facility for overseas adoption to meet the needs for parenting of infertile couples.²⁰ On the other hand, the desire for genetically related children is a very powerful one. Every technology has its early and costly experimental phase. Judgments by people for whom having children may be no difficulty must be rendered sensitive to the enormous motivation

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of those who make heart-rending sacrifices to secure their own child.

<u>Psychoanalysis</u> - No branch of medical care is now escaping this debate. Even psychoanalysis is now coming in for scrutiny. G H Mooney, writing in the Journal of Medical Ethics has said:

"It is not a question of ethics or economics. Without a wider use of economics in health care, inefficiencies will abound and decisions will be made less explicitly and hence less rationally than is desirable ... The price of inefficiency, inexplicitness and irrationality in health care is paid in death and sickness. Is that ethical?"²¹

Applying this to the field of psychoanalysis, Dr Greg Wilkinson of the Institute of Psychiatry in London has written that pscyhoanalysis is highly expensive and limited in its application to "integrated wealthy and functioning individuals who are interested in learning more about themselves or who need to relate their personal problems to a strong figure." He adds that the "disconcerting aspect" of psychoanalysis is that it "drains resources from the care of seriously mentally ill patients". He questions the place of psychoanalysis and psychoanalytically-oriented psychotherapy in the nationally funded health service:

"There are pressing clinical, research, economic and ethical reasons in support of the contention that an urgent review of the extent and impact of psychoanalytic practises in the National Health Service is called for."²²

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<u>Emergency wards</u> - The great concentration of expenditure in emergency wards derives, in turn, from the high technology used in these wards. A crude way of bringing home the hard choices to be made is the assertion that one possible way to prevent the increasing cost of health care is to reach "significant agreement on the proper care of the dying", ie that in some cases heroic treatment will <u>not</u> be offered. Drs Crispell and Gomez of the Universities of Virginia and Chicago respectively, write:

"One of the costs which will surely be evaluated is the cost of terminal care for dying patients in a hospital setting. то re-emphasise, the single most expensive medical bill at this time in America is for last week of life in an acute care the If we decrease the dollars spent hospital. for hospitalisation for the last year of life, might these savings be more properly allocated to other health programmes which would be more beneficial to all of society? In that the Federal tax dollar supplies over 50% of the funds spent for health care, the total amount and the allocation becomes a political issue. The distinction between non-economic and economic concerns must be made even more specific. If we had unlimited funds for measures which prolong death, should we use them? This will be the major economic-moral question to be answered if economic constraints prevent "proper care of the dying". The slogan "Death with Dignity" emerged when over-treatment of patients became a threat. Will economic constraints bring the threat of under-treatment of patients?"23

<u>HIV/AIDS</u> and <u>AZT</u> - No discussion of modern medical ethics can take place without reference to AIDS. This major global pandemic presents very great challenges of

a clinical, ethical, economic and legal character. Whole books are now being written on the economics of No examination of the subject can be free of a AIDS. reflection upon its economic impact on virtually every land.²⁴ The need to shift scarce resources to an entirely unexpected epidemic puts new, unpredicted and acute burdens on medical administrators, bureaucrats and politicians. So far, the drugs available to arrest the vicious progress of the human immunodeficiency virus (HIV) are only partly, and temporarily, effective. The best known of these is Zidovudine (AZT). But this and other drugs are extremely expensive. Until a recent reduction in price, the average cost of keeping a patient in Australia on AZT approached \$10,000 per year. Yet, for those able to use the drug successfully, the change in the quality of life is remarkable. Such people, and their families and friends, react with impatience at the suggestion that the substantial resources devoted to this temporary palliative would be better spent in community education and prevention of the further spread of the virus. In this, they merely reflect the "rescue principle". Reactive medicine, to which we have become accustomed, seeks to rescue people from dire predicaments. AIDS is just the latest of these. It is difficult to get people very interested in the anonymous statistics of illness prevention when a real,

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live, desperately urgent patient needs immediate costly therapy. The ethical choices which face developed countries in this regard are not pressing in the developing world. They simply cannot afford the resources to provide AZT or like therapies to those of their citizens ill with the "slim disease". In an African state, where the average annual expenditure on public health may be as low as \$8, the provision of AZT is just not on the agenda. Yet, as therapies and drugs are developed, an ethical question is posed. Should these, effectively, be limited to the developed world? If so, for how long and upon what principle? In the one world, where the challenge of AIDS is truly global the ethics of medical choices must also be seen as global.

EXPOSING OUR CRITERIA FOR CHOICE

What conclusions can be drawn from these cases? Some commentators suggest that the problems are so difficult that it is virtually impossible to derive any generally acceptable principle to guide ethical decision-making to which price tags attach.²⁵ Speaking of the principle of "rescue", Professor Jonsen concludes:

"Should the rule of rescue set a limit to rational calculation of the efficacy of technology? Should we force ourselves to expunge the rule of rescue from our collective moral conscience? How should law deal with this powerful moral imperative? Might a world with less cost-effective health care be a morally better place?"²⁶

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It is easy to pose the questions. Doing so has its own utility. But the answers come more slowly.

Posing the questions at least drives us to a consideration of basic philosophical principles. When we do so, we realize that there are competing theories questing for our acceptance. Probably the utilitarian principle is the most popular with bureaucrats and politicians. By suggesting the maximisation of the greatest utility to the greatest number, this provides an attractive counterpart to the democratic theory and the politician's constant quest for the votes of the majority.

But thoughtful commentators remind us of the competing ethical views of Immanuel Kant. According to these views, every human being has an inherent value as a being with a capacity for reasoning and moral awareness. As such, each human is equal in terms of value to each other human. Kant did not deny that there were inequalities, in ability and talent as well as inopportunities and status. Nevertheless, as recently explained:

"He would argue that as we make decisions that affect our interactions with others, we do not have the moral right to treat another human being as less human or less worthy of regard than others. It is doubtful that Kant ever thought about medically prolonging the life of severely handicapped newborns, since the necessary technology was not available during his lifetime. However, if his philosophy were extended to this situation, a Kantian would find it morally reprehensible to make medical judgments regarding individual worth based on differences among us, including profound mental and physical defects. In other words, according to Kantian views, everyone should have the same access to life-saving treatment."²⁷

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This approach contrasts with the popular utilitarianism which, perhaps not surprisingly, was the product of English philosophers such as John Stuart Mill, Jeremy Bentham and Henry Sidgwick. They would consider that the critical question to be asked, in the case just mentioned, was "whether the community would gain more than a severely handicapped infant would lose from the withholding of medical Many find such questions, baldly posed, to be treatment". offensive to the moral sense of the dignity and worth of each living human creature. They argue, for example, that a society which downgrades its respect for the severely handicapped and its least fortunate members generally enhances its own capacity to survive because of its adherence principles. fundamental moral They point to the to experiments of the Nazi doctors and their justification of what they did on utilitarian lines. Sometimes the sums are not enough.

Somewhere between the Kantian philosophy and the utilitarian cost-benefit analysis lies the approach of the contemporary philosopher John Rawls.²⁸ He asks individuals to make moral decisions on the basis of what they would like done to them in a given situation and to imagine a society in which their situation would be unknown to them as decision-makers. In such a society, the decision-maker would have to consider the needs of the disadvantaged. He or she would allocate rights and privileges accordingly. Upon this analysis, family members and medical practitioners might make

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a perfectly justifiable moral decision to withhold treatment because they believed that society would not deal a fair hand to a handicapped infant's life, given its disabilities.

This is not the occasion for a philosophical treatise. But the hard choices of an ethical character posed by advances in modern medical technology force us back to fundamentals. They force us to identify our philosophical major premises. This is itself a useful process, so long as it does not delay, by indecision, the making of critical choices both at a macro and micro level. Furthermore, we must recognise that there is, as Smith says, no unifying philosophy in modern secular conditions. Social philosophy will change over time. It also varies from place to place. For example, empirical studies of medical approaches to the use of advanced technology for severely handicapped neonates demonstrates significant differences between the approaches taken in Australia and Poland.²⁹ These may be ascribed to differing religious and cultural features of each the society. Such differences help to teach the point that universal criteria are unlikely to be attained.

THE CULTURAL VARIANTS IN DECISION-MAKING

Similarly, studies of ethical choices in the provision of scarce technology to young and old patients demonstrate that, in some societies, the young will be favoured. In others the old. An interesting survey in Cardiff, Wales posed for 721 randomly selected individuals the question how they would react to ethical problems. If two people,

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identical except for age, present for medical treatment for a life-threatening condition and only one can be treated, how should the choice be made? The authors of the study concluded:

"Many people react with distaste at an attempt to ascribe a value to a particular human life. When faced with the hypothetical question of how much time, effort and resource should be invested in trying to save a particular life there is a widely held view that no exercise should be spared. Yet there are analyses which demonstrate that society behaves as if there is a finite and not a very large value of a life and therefore the amount of resource that may be invested to try to preserve that life. This is inevitable, since the demands made upon society exceed its finite resources."³⁰

Surprising to me in this study was the conclusion that, when choosing between a two-year-old and eight-year-old child, the choice was for the older by a ratio of 5:3. Yet asked to choose between making facilities available to one patient and to choose between the one aged 5 and the other aged 70, both with leukaemia, only 1% chose the older. Ninety-nine percent chose the younger. Most of them said it was "very easy" or "quite easy" to do so.³¹

This result in Cardiff contrasts with reports of the response of African tribes to similar obligations of choice. The Akamba people of Kenya, for example, would favour an older person over a younger person. This is explained by Professor Smith:

"The Akamba insist that life is much more than "atomistic sums of individual economic contributors". Rather it is viewed as "a social fabric of interpersonal relations". Thus, under

their philosophy, the more advanced age a person reaches, the more strongly related that person becomes to the lives of others and the greater wisdom he shares with the community. This relationship is thus viewed as a significant social resource. Similarly, a man without children would be saved over one with five. [I]n the United States an opposite position would be taken - with the view that for the sake of the children their father should be treated medically and saved. The Akamba maintain "that the man without children faces annihilation and must be allowed to live so that he can 'raise up a name' for himself by having children.³²

These illustrations of responses to similar problems in four continents show that it may be dangerous to search for universal rules. The solution to the ethical quandaries we are discussing derive very much from local cultural norms.

THE BRAVE ATTEMPTS AT COST-BENEFIT ANALYSIS

However, some writers have attempted to reduce those norms to a scientific formulae. A typical analysis is that of M C Weinstein and W B Stason.³³ They attempt the expression of formulae which take into account direct and indirect costs of hospitalisation, physician time, medications, laboratory services, counselling and other ancillary services together with a component for the adverse effects of treatment and another for savings in health care, rehabilitation and custodial costs resulting from the prevention or alleviation of disease. By their equations, a component must also be allowed for the cost of treating diseases which would not have occurred if the patient had not lived longer as a result of the original treatment.

They then compare these costs with quantitative

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measures for the increase in the expected number of liveyears. But they acknowledge that it is necessary to inject a controversial factor for "quality-adjusted life years". Of course, this introduces unscientific, or at least unmeasurable, factors which import matters of opinion upon which there may be no consensus. The approach is an interesting one. It does the service of identifying some of the considerations which are otherwise taken into account only subconsciously. But it cannot pretend to a complete analysis. For example, it makes no provision for the opportunity costs involved in providing a particular treatment or technology to a particular patient. Might there have been greater benefits in spending that resource on another technology available to more people? Or in spending the funds on prevention rather than treatment of ill health? on education or beautification of the environment? Or Attempts to devise a formula can do no more than identify some of the chief immediate factors. The economic ripples are often unforeseen. They cannot all be measured.

The advantage of bringing these issues out into the open, which technology has stimulated, are obvious. Many writers express this thought:

"At present these decisions are taken by a large number of physicians working in isolation, and the result is a haphazard aggregation of individual decisions. Effectively, society is represented in the decision-making process by samples of one, which we suggest is unrepresentative and thus inescapably unsatisfactory. Society should not ask doctors to bear the burden of this decision-making, not only because it is inefficient but also because

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the choices (as distinct from the implementation of those choices) should have a social rather than a professional base."³⁴

The exposure of the facts of choice may lead to a more public scrutiny of the criteria by which choices are made. This, in turn, will facilitate patient choice and autonomy. If the facilities are inadequate, this fact will become known and not hidden behind paternalistic professional relationships or well meaning but idiosyncratic decisions. As well, doctors will then "stop covering up for an inadequate health service". They will bluntly disclose the choice to be made between death and scarce resources for dialysis.³⁵ Professor B V Johnstone contrasted this openness with the alternative:

"Physicians, acting as gatekeepers, exclude some patients on a priori economic grounds based on government policies. Physicians might conceal the economic and political reasons for the policy behind statements that the patient is not suitable, or simply not mentioning the availability of the treatment. Such a process would violate justice in excluding the patient from being a participant in the decision. It would be morally questionable in inducing the physician to violate the requirements of his moral agency, specifically to forego the role of advocate for the patient, and to fail to honor his trust relationship with the patient."36

ADOPTING PRINCIPLES AND STRINGENT PRACTICES

These are the reasons why many commentators on this subject see as vital the exposure of the problem so that proper procedures and criteria may be developed. Professor Margaret Somerville expressed this thought well. She did so at a conference in Sydney and in a paper with the provocative title "Should the Grandparents Die? Allocation of Medical Resources with an Aging Population."³⁷ She took that title as a deliberate inversion of the well known question by Dr Kühse and Professor Singer "Should the Baby Live?". She concluded:

"Unfortunately, we may not be able to find any "right" answers - ones that harm no one - in allocating medical resources with an aging population. We can, however, use "right" decision-making principles and processes. General goodwill and personal conscience and integrity are essential traits, but not sufficient approaches or safeguards in dealing with the issues raised. Examined cognitive and emotional responses and structures and disciplined procedures are also necessary. To develop these is one of the major challenges for contemporary health law and ethics. Such development is essential in the search for answers to the companion questions of "should the baby live?" and "should the grandparents die?". These answers will reflect some of the most important aspects of the ethical and legal tones of our communities as we prepare to enter the 21st century."³⁸

There are, of course, some who argue that an intuitive approach to decision-making and reasoning on these questions is more reliable and less self-deceptive than attempts at formulae and equations.³⁹ But the danger of intuition and generalised reasoning (such as we are used to in the courts) may be that their procedures mask preconceptions and prejudices. They may obscure assumptions and the premises for decision-making. Just as technology reflects a more scientific world, so our ethical decisions must aspire to greater precision, clarity and accuracy. In the end, in

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resource allocation, whether on a national or individual level, a leap of judgment will be called for. That may ultimately involve intuition. But that judgment will be better informed and more likely to be just if it is made after the efficient exposure of the most relevant preconditions for it. Not only will that submit those preconditions to individual and social criticism and possible change. It will also impose on the decision-maker a discipline and self-scrutiny which the importance of the decisions to be made properly demands.

Amongst the many blessings for which we must be grateful to technology is the new urgency with which technology has required us to face squarely the economic facet of ethical decision-making. The issue is an uncomfortable one. But it will not go away. It was always there. Technology insists that we attempt the answers.

FOOTNOTES

President of the Court of Appeal, Supreme Court of New South Wales, Sydney, Australia. Commissioner, World Health Organisation Global Commission on AIDS. Governor, International Council on Computer Communication. Commissioner International Commission of Jurists.

- A R Jonsen, "Bentham in a Box: Technology Assessment and Health Care Allocation" in Proceedings, American Society of Law and Medicine, <u>Law, Medicine and Health</u> <u>Care</u>, Sept 1986, 14:3-4, 172.
- 2. D V Johnstone, "Justice and Cost-Containment in End-Stage Renal Disease" 3 J of Contemp Health L and Pol'y 65, 84 (1987).
- 3. Jonsen, 174-5.
- G P Smith II, "Death be not Proud: Medical, Ethical and Legal Dilemmas in Resource Allocation" 3 J of Contemp Health L and Pol'y 47, 48-9 (1987).
- 5. R Donley, "A Brave New World of Health Care", 2 J Contemp Health L and Polly 47, 51 (1986).
- This account is taken from <u>The Times</u> (London) 9 January 1985, 2 and The <u>Lancet</u>, 19 January 1985, 176.
- 7. The Lancet, 19 January 1985, 176.
- 8. Mr L Carter-Jones cited The Times, 9 January 1985, 2.
- 9. Mr C Paine, guoted The Times, 9 January 1985, 2.
- 10. Mrs Elizabeth Ward quoted <u>ibid</u>. See also <u>The Lancet</u>, 18 February 1984, 386 ("End-Stage Renal Failure: the Doctor's Duty and the Patient's Right")
- 11. Cited The Guardian, 9 January 1985, 10.
- 12. <u>The Times</u>, 10 January 1985, 12.
- 13. Ibid. See also Johnstone, 78; Smith 61.
- 14. Smith, 61.
- 15. <u>Ibid</u>.
- 16. British Med J, 16 February 1985, 527.

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- 17. See discussion (1985) 142 Med J of Aust, 60.
- 18. Ibid.
- 19. Ibid.
- 20. Z Cowen, "A View from the Clapham Omnibus" in 14 Law, Medicine, Health Care, 3-4, 108 (1986).
- 21. G H Mooney, "Cost-Benefit Analysis and Medical Ethics", J Med Ethics, 1980, 6, 177-9.
- 22. G Wilkinson, "Psychoanalysis and Analytic Psychotherapy in the NHS - a Problem for Medical Ethics", <u>J Med</u> Ethics, 1986, 12, 87-88.
- 23. K R Crispell and G F Gomez, "Proper Care for the Dying: A Critical Public Issue", <u>J Med Ethics</u>, 1987, 13, 74.
- 24. J E Osborn, "Public Health and the Politics of AIDS Prevention" 118 Daedalus, 3, 123, 135 (1989).
- 25. See eg Jonsen, 174.
- 26. <u>Ibid</u>.
- 27. D S Huefner, "Severely Handicapped Infants with Life-Threatening Conditions: Federal Intrusions into the Decision Not to Treat", 12 <u>Am J L and Med</u> 171, (1986).
- J Rawls, "<u>A Theory of Justice</u>", 1971. See discussion Huefner, 198-199.
- 29. Z Szawarski and A Tulczynski, "Treatment of Defective Newborns - a Survey of Paediatricians in Poland", <u>J Med</u> <u>Ethics</u>, 1988, 14, 11.

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- 30. P A Lewis and M Charny, "Which of Two Individuals Do You Treat When Only Their Ages are Different and You Can't Treat Both?". In <u>J Med Ethics</u>, 1989, 15, 28.
- 31. <u>Ibid</u>, 29.
- 32. Smith, 60.
- 33. M C Weinstein and W B Stason, "Foundations of Cost-Effectiveness Analysis for Health and Medical Practice", 296 <u>New Eng J Med</u>, 716 (1977). Quoted in W J Curran and E D Shapiro, "<u>Law, Medicine and Forensic</u> <u>Science</u>", 3rd ed, Little Brown and Co, Boston, 726.
- 34. Lewis and Charny, 28.
- 35. E D Ward, "Dialysis or Death? Doctors Should Stop Covering for an Inadequate Health Service" in <u>J Med</u> <u>Ethics</u>, 1986, 12, 61.
- 36. Johnstone, 84.
- 37. M A Somerville, "Should the Grandparents Die?" Allocation of Medical Resources with an Aging Population, 14 <u>Law Med and Health Care</u>, 3-4, 158.
- 38. <u>Ibid</u>, 163.
- 39. See eg George J Agich and G E Bagley, "The Price of Health". Reviewed G Bevan in <u>J Med Ethics</u>, 1988, 14, 53.

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