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Buying Time: A Theological Perspective on Ethical Issues
of High Technology Innovations in Medicine --
Heart Transplantation

Roger Allen Balk

A Thesis
in
The Department
of
Religion

Presented in Partial Fulfillment of the Requirements
for the degree of Doctor of Philosophy at
Concordia University
Montréal, Québec, Canada

March 1988

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ABSTRACT

Buying Time: A Theological Perspective on Ethical Issues
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Roger Allen Baik, Ph.D.
Concordia University, 1988

The contribution made by theology to contemporary bioethics is in dispute. It can be shown, however, that the theological concept of time can be developed in such a way that it illuminates the transformation brought about by high technology medicine. We have taken, as an example, the effects of human organ transplantation upon some diseases which have normally shortened the human lifespan. Using heart transplantation as representative of this high technology, we show the ethical changes which have occurred as a result; and, how they affect our understanding of time as autonomy, and processes like selection for survival and societal responsibility. In addition, the organization of this activity into a health care system has also altered practices such as physician authority, hospital organization and government regulation and evaluation of these services because it must deal with allocation of limited resources between burgeoning immediate needs and the rights of future generations.

Finally, because transplantation is dependent upon the

use of vital organs from persons who are legally dead, it raises a multitude of difficult questions about determining legal death, respect for the "living dead" and the relative value of those who could live if they receive a transplant versus those who cannot live but who could contribute a vital organ. This requires a new form of social response. It is argued that in a pluralistic society, the church as a community might make a major contribution to the dialogue required to establish the social consensus necessary to maintain control over high technology medicine.

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INTRODUCTION

Just how significant is the contribution of religion to developments in the field of bioethics? The word itself is of recent origin¹ and incorporates many subjects which previously were largely the province of Catholic moral theologians. Their subject matter was determined by the general themes of moral theology and most frequently subsumed under discussions concerning the Decalogue or the Sacraments²:

A. The fifth precept

1. Mutilation
2. Extraordinary Means
3. The principle of totality
4. Sterilization
5. Transplant Surgery
6. Psychosurgery
7. Experimentation on Human Beings
8. Abortion
9. Ectopic Operations
10. Euthanasia

B. The sixth precept

1. Masturbation
2. Contraception

- C. The eighth precept
Professional Secrecy

II. The Sacraments

A. Marriage

1. The role of sex in marriage
2. Impotence
3. Sterility Tests
4. Artificial Insemination

B. Extreme Unction

C. Care for the dying.³

In order to grasp the significance of this way of organizing the subject some further amplification is in order. Charles Curran in his historical analysis of developments in Catholic moral theology has called attention to the fact that moral theology as a discipline had over the years become increasingly divorced from its basis in theology⁴ with the result that it had become cut off from new developments in both religion and society. There had been no equivalent systematic development of medical ethics within the Protestant tradition that could claim even the dubious tag of "outdated."⁵

The Protestant silence was broken in 1954 with the publication of Joseph Fletcher's Morals and Medicine.⁶ Such was the challenge of Fletcher that it forced those not previously interested in the whole topic to reconsider their neglect.⁷ It also required Catholic moralists to both defend and reconsider their whole perspective on moral theology. He

challenged the notion that it is possible to derive from the scrutiny of nature the identifiable will of God or even for that matter specific norms governing the behaviour of human beings.⁸ He argued that changes in the amount of knowledge available required a corresponding response in the morality that emerged from this new situation. He insisted that the human moral condition was one which was free from many aspects of its setting in nature. Finally, he placed his conclusions in a context "within the range and provision of Christian theology, but that would be all that could be claimed for them."⁹

Reading Morals and Medicine today, one is struck by the fact that Fletcher's work signals the direction of many of the current developments in what has become bioethics including, I believe, the name itself. He also points to areas which will emerge as problematic for the ongoing relationship between religion and bioethics. It will be helpful to our argument to make these issues quite specific:

1. The current state of knowledge on a given subject has a key role in determining how it is subsumed for purposes of ethical analysis.
2. The basis of norms tends to be seen as issuing from a social source rather than one which is determined by nature interpreted either in the sense of emergent "laws" or the revealed will of God.
3. The specific role or contribution of religion to ethics thus becomes more problematic. This

situation is intensified by the pluralistic structure of contemporary society and by the drive to develop rational bases for ethical norms.

Subsequent religious, and somewhat more belatedly, philosophical involvement in bioethical issues appear to follow a pattern which is surprisingly similar to that set forth in the published version of Fletcher's 1949 Lowell Lectures. The ups and downs of the debate which he touched off are important additions to the situation which we are trying to summarize.

The arid and formally structured Roman Catholic efforts in ethics and moral theology were also challenged by the developments of the Second Vatican Council. The questions about methodology which Fletcher considered to be basic to his whole presentation¹⁰ turned out to be critical for the future of Catholic thought as well.¹¹ Since 1965 a great deal of energy has been expended in Catholic circles in the attempt to reconcile the conflict which has arisen between those with a primary interest in developing new methods and those concerned in maintaining intact the structures of hierarchical authority.¹² One of the major points at issue here would seem to be the desire to maintain a position which reflects the claims of Christianity as to the final truth of its teachings. The tendency of much Catholic thought has been to see this issue in the context of religious freedom, a direction not altogether immediately relevant for many bioethical issues. The theological implications of the role of Christianity in a pluralistic society were more a feature of the Protestant

reflections on the basis of ethics. These have been stimulated to a great degree by the emerging concern of Protestant thinkers with issues which arise from the bio-medical scene.

Here it is important to consider the contribution of Paul Ramsey to the development of bioethical thought. His 1956 article "Freedom and Responsibility in Medical and Sex Ethics: A Protestant View,"¹³ which was in fact a review of Morals and Medicine had two important effects: it established Ramsey as a mediating influence between Catholic and Protestant thought on bioethics and it tried to establish a method for incorporating Protestant theological principles into a coherent approach to bio-medical ethical issues. It was, however, not until 1970 and the publication of The Patient as Person: Explorations in Medical Ethics¹⁴ that Ramsey brought forward a position with such coherency that it attracted wide attention in academic and medical circles generally. The subject matter of this book reads like the content of the contemporary bio-ethical debate and Ramsey's work did much to form the systematic structure of the problems and issues which have come to characterize the present situation. Ramsey also acknowledged his debt to the rational tradition of Catholic moral theology and did much to encourage a Protestant form of casuistry for attacking the specific case. Looking forward and at the same time reviewing the effects of this work, it is possible to see in this book the limitations which were to restrict the religious contribution to later developments in bioethics.

Structurally speaking, the theology in the book was confined to the general introduction. When he began to discuss specific issues Ramsey employed categories and terminology which was essentially secular or at least without specific religious reference,¹⁵ which had the effect of attracting followers because they were of a similar genre in social and moral outlook. The inherent limitations of his assumptions were not too apparent at the time. It may not be too much to say that his approach was reflective of a dying Christian society whose vocabulary had been absorbed in a pluralistic culture. The key to this issue is found in the style of apologetic it employs -- the use of secular terms which for the religious person are capable of claiming a religious ground. In the old society this approach made a lot of sense to most people, in the new pluralistic culture it was unconvincing.

For a time, this caveat was unnoticed since the list of things to do which came out of The Patient as Person was so extensive that it absorbed the energies of a long list of interested Protestant and Catholic writers and scholars and it also stimulated secular philosophers to claim a piece of the action as well.¹⁶

Rather than follow the details of the development of bioethics which ensued from the publication of Ramsey's book, I would like to turn to an examination of the effects which this in-depth immersion in ethical issues had upon both theologians and philosophers working in the field. First a

quotation from Gordon Kaufman:

That the contemporary theological scene has become chaotic is evident to everyone who attempts to work in theology. There appears to be no consensus on what the task of theology is or how theology is to be pursued. Some see it as the 'science of religion'; others as exposition of the Christian faith; still others as prophetic pronouncement on the conditions of, for example, contemporary American culture (or Western culture [sic] generally). There are those who are attempting to develop a 'non-sectarian' theology which will not be restricted in meaningfulness to any of the great historic religious traditions; others are attempting to exploit theological insights for developing a more profound understanding of human nature; yet others still see theology as primarily a work of the church attempting to come to a better understanding of itself.¹⁷

Now one from Alasdair MacIntyre:

The inability of philosophers to reach agreement is notorious. And this inability extends to disagreement over how to characterize their disagreements and as to which of their disagreements are central to their discipline and which peripheral Contemporary moral philosophy is likely to suffer even more from this endemic inability to agree than are such other sub-disciplines as logic or epistemology; for differing standpoints within moral philosophy have always been closely related to differing moral standpoints. And our own is one of those periods in the history of morality when the deepest moral divisions exist in areas of central human concern ...¹⁸

Both disciplines had to take notice that the implications of the pluralism of thought which existed among its practitioners had an impact beyond the academic circles to which it was traditionally confined. Ethical theories, which in turn are based upon moral standpoints, were now being tested in the demands of the decision-making requirements of contemporary society such as medicine, and what has been an academic debate now has to answer to a more stern interrogation. What this means, for those attempting to continue

to respond to the demands of bioethics from a religious point of view, is a need for careful attention. The extent of the problem is best indicated with a series of questions and the debates between the theologians Paul Ramsey and James Gustafson and the philosophers Alasdair MacIntyre and Hans Jonas afford the opportunity to examine the evolution of the issues which we have summarized below.¹⁹

1. Who should actually pay attention to the views expressed from a religious point of view?²⁰
2. How is a social consensus reached when society itself is composed of many groups with differing points of view?
3. How are the adherents of the Christian tradition to explain both to themselves and to outsiders the significance of their diversity about issues affecting human behaviour?
4. Does Christianity have any thing unique to contribute to the development of bioethics?²¹
5. Is it possible to argue convincingly that ethics provide a stance which is independent of a religious tradition and thus subjecting it to an outside moral analysis?²²

From this time onward there is a marked tendency for theologians and philosophers to go their own way as the issues and diversity of the emerging problems considered under the rubric of bioethics left plenty for everyone to do. The divergences become less important because the subject

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became sufficiently developed to assume its own institutional life with the major differences being resolved through the agency of a third party: the Courts.²³ The actual clinical practice in which ethical issues were dealt with was more and more covered by protocols and conventions concerned with the actual making of decisions, a typical example being the hospital ethics committee. In the United States, the series of Presidential Commissions brought forth a number of consensus type reports which pointed the direction for administrative practices and legislation aimed at creating a basic ethical character to research with human subjects and a host of similar issues.²⁴ It is interesting to note that these Commissions included within their membership ethicists of both a theological and a philosophical persuasion.²⁵ Equally striking is the number of papers which these bodies solicited from theologians and philosophers.²⁶

A vast body of bioethical activity had now been created which included not only several specialty journals, countless books, several important research centers and think tanks and congresses and symposia too numerous to catalogue. One important characteristic of the ferment which had been generated was the use of the court system as the means for resolving several of these disputes which are at best only marginally legal in nature. While the legal system may be the best available solution for the airing and adjudication of issues which are deeply emotional and socially disruptive, it is generally recognized that the law is no substitute for

the moral underpinning of a society. This sentiment, in turn, has led to several ventures into an analysis of the social setting of morality which has included works from several writers who were already mentioned.

There is, first of all, Alasdair MacIntyre's After Virtue.²⁷ This is an attempt to construct an alternative to a theological teleology as the basis for a moral theory of absolute obligation. Rejecting Kant's attempt to found such a theory on individualist assumptions, MacIntyre tries through an historical analysis of western philosophy to put together with the help of Vico and Hegel, a concept of the grounding of morality in the historical and social life of humankind. While he may not be finally successful,²⁸ he points to a direction which has been that of some interest to theologians also: that is, some fresh initiatives in the areas of moral, political and social theory and in the philosophy of history.

One of MacIntyre's partners in the earlier discussions sponsored by the Hastings Center, James Gustafson, has also noticed many of the same problems which have attracted the former's attention. Ethics From a Theocentric Perspective²⁹ summarizes the perspective that he has developed over the length of his career. Deeply colored by a view of society nourished by modern sociology, he argues strongly for the need for other ways of construing the world to effect theology. Historic religious traditions are a part of the community of human knowledge and understanding, and theology is a way of interpreting and understanding this reservoir of

wisdom and discovery. The basis of obligation is found in the way "things really and ultimately are"³⁰ which suggests some limitation on the anthropocentrism characteristic of Christian theology and much contemporary thought.³¹ At the same time, Gustafson does not direct his development of ideas towards a new version of natural law. They are rather the result of the process of "discernment," a term of major importance for his work. It is his way of describing the process of knowing/valuing under the conditions of human finitude.³² Does he, however, come up with a satisfactory answer to MacIntyre's demand for a unique role for the theological ethicist? Here is his reply. It is important to note it has two parts:

I do not need to develop these matters further to make my general point that those most rational of thinkers about ethics the moral philosophers, share a common purpose of finding a rational basis for morality on which all rational persons can agree. I do not need to develop these matters further to make my point. Yet the fulfillment of that purpose has eluded them; one need only read in a cursory manner the countless pages of discussion in the last four decades in philosophical journals and books to be overwhelmed with the detailed attention they give to each other's work in order to show where it is in error.³³

A theologian working in ethics is much informed by these discussions (but) He certainly cannot hope to persuade the moral philosophers that proper moral theory must be theocentric, and that evidences can be adduced to support a theocentric view in such a way that there is no 'nonrational' move or moment in the development of it.

In noting with approval an observation of Hans Jonas, Gustafson seems to be struggling to introduce the basis of a moral stance capable of coping with the demands of contemporary technology:

The general direction of moral philosophy is to make man the measure of all things.³⁴ Indeed, as one moves from utilitarianism in which the consequences of human action are measured -- to be sure in terms of their benefits to human beings -- to ethics developed from recent action theory, man as the measure becomes even more restricted in scope. Certainly there is nothing like the 'will of God' against which to test the propriety of human intentions and actions; certainly there is no longer anything like the moral order of the universe to which human actions are to be conformed The theologian can and must reflect upon human experience in its moral and other dimensions in such a way that an alternative view of the ethical can at least be intelligible to the moral philosopher ...³⁵

We have tried to show how the discussion typified by MacIntyre and Gustafson is representative of that which has gone on in the development of the discipline of bioethics. There is more than a hint in this exchange of larger issues which are a part of the contemporary struggle to understand moral development in both personal and historical terms. For the time being at least one of the effects of the pluralistic structure of contemporary society under the influences of the high-technology revolution is the inability to decide controversial moral issues without reference to the Courts, a service for which they are not necessarily particularly qualified.³⁶ In the meantime there is no lack of opportunity for the bioethicist to ply his trade because the ordering and structuring of decision-making has emerged at the clinical and policy levels as a moment with moral content and importance. At the same time, because of its nature, decision-making has frequently been regarded as primarily an act of technical manipulation and often downgraded by moralists as a perversion of their real

responsibility,³⁷ and left to the attention of other analysts. However, this may be a mistake and we now turn to suggesting why.

1. The terminology, which is used to evaluate the high technology applied in contemporary medical practice, is not that traditionally used for ethical analysis and yet it becomes the vehicle by which moral intentions and effects are calculated.

2. There is a consequential bias to any evaluation applied to medical practice, but this by no means allows for a preempting of the field to those of utilitarian bent, because the values upon which decisions are based reflect other standards than the greatest good for the greatest number.

3. Since specific application of statistical probability is always problematic, issues of personal and delegated responsibility are always present and constitute the stuff from which moral awareness and courage are manifested.

4. If "to say something theological is to say something ethical,"³⁸ then to reconstruct the ordering³⁹ going on in the use of technology is to bring it into a moral structure and insure that it is responsible to the interdependence of all creation which is one measure of "how things really and ultimately are." The risk in such an operation is considerable, since it is quite possible that what emerges will not be recognizable as ethics in the sense that has been largely accepted throughout western cultural history and certainly in recent moral philosophy,⁴⁰ in addition to the fact that

it may not be accepted as theology either!

In spite of the risks involved, we propose to examine the concept of time as a means of illustrating the moral and ethical dilemmas introduced by the application of high technology to the practice of medicine, as well as to suggest how theological commitment may continue to illuminate the human condition of finitude and self-deception.

There are different ways in which experience of time may be organized and connected to the framework of human social institutions.⁴¹ Christian theology and its accompanying views of human society have been dominated by St. Augustine's reflections on the nature of time.⁴² According to this view, temporality (represented by the civitas terrena) is of lesser value than the quality of life which finds its rest in the life with God (the civitas dei). Augustine depicts these opposing states of awareness as coming into existence because the inhabitants of the Two Cities are locked in a conflict which is the principal feature of this present age.. This cosmic confrontation is also reproduced on the individual level. It is a key part of the struggle which occurs in us as persons who have to come to some understanding of the meaning of finitude. We are conscious of the fact that our individual time (lifespan) is an irreversible span over which we have very limited control. The issue of control itself becomes the source for many of Augustine's most creative images. He is quite clear, however, in his belief that our attempts to seize control over that which is set by God alone

constitutes the most basic expressions of our sinfulness unto death. Not surprisingly, nature as one of God's creations, reflects in its order the same sense of time as a pre-set limitation which Augustine reads in the human condition. Indeed in this sense we are part of nature.

Since the fourth century, there is not much in the history of human experience to contradict that sentiment even if a somewhat different vocabulary is introduced.⁴³ This condition, however, has become radically modified by discoveries in medicine that began with the development of a vaccine for small-pox and finds its present day expression in the respirator, the coronary by-pass machine and heart transplantation. Essentially what these developments have done is to suggest that finitude is not exactly what it was previously made out to be even though it is far from being abolished.

Theologically speaking, some of our most cherished symbols of finitude have been destroyed or radically modified as the result of these technological innovations. Our image of the heart, breathing, what constitutes death or even an essential body part has had to change and with it the personal and social sensibilities and structures that these images have provided for use as a way of construing the moral implications of our finitude. It seems also to be the case that this form of thinking is not confined to those vestiges of religious life which remain in this part of the 20th century. For example, there is a great deal of difficulty

incoming up with words which describe adequately the condition and status of a brain dead potential organ donor.⁴⁴ Some reports suggest that individuals receiving transplants have some difficulty with their resulting body images.⁴⁵ It is still the frequent feeling in Intensive Care Unit situations that stopping artificial life support in a brain dead patient is causing his death.

We would like to introduce the concept of "buying time" as an appropriate term to describe the results of high technology medical interventions and to depict the unprecedented ethical conditions which these practices introduce. It will be our contention that time is a consistent referral point in the discussion which is provoked by consideration of the value of a technological intervention of the type which Jennet has called "rescue."⁴⁶ The term suggests also the existence of a larger perspective against which the particular intervention must be played. This background includes a social context which involves other needs and values. In addition, it leaves room for indicating a meaningful theological ordering which would be part of the givenness of existence. While, strictly speaking, the notion of buying time does not suggest that several versions of medical technology in use today actually make time go backwards, the interference with the accepted notion of human lifespan is sufficient to render it essentially useless as a standard for evaluating the worth of these activities both socially and individually, particularly in view of their great cost.

"Buying time," as a concept, introduces us to the great need for providing a moral means of analyzing human ability as it meets the possible restrictions imposed by individual and social costs; and the image enables us to maintain some connection with our moral traditions.

Heart transplantation is the practice which has been selected for analysis using this extended notion of time as a moral value. It is a good representative of much of medical practice involving high technology because it is very expensive, quite successful, has considerable risk, presents many unknowns and appears to have a limited effect (5-10 years), requiring regular sophisticated medical oversight.⁴⁷

Footnotes to Introduction

¹L. Walters, "Religion and the Renaissance of Medical Ethics in the United States: 1965-1975," in E. Shelp, Theology and Bioethics (Amsterdam: D. Reidel, 1985), pp. 3-16; Van Renessalaer Potter, Bioethics: Bridge to the Future (Englewood Cliffs, New Jersey: Prentice Hall Biological Series, 1971) is credited with the first use of the term; D. Callahan, "Bioethics as a Discipline," The Hastings Center Studies, 1, No. 1, 1973, pp. 62-73; K. Danner Clousner, "Bioethics, Some Reflections and Exhortations," Monist, 60, 1, 1977, pp. 47-61; "Bioethics," Encyclopedia of Bioethics (New York: Free Press, 1978), Vol. I, pp. 117ff.

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³L. Walters, "Medical Ethics in New Catholic Encyclopedia, Vol. XVI, Supplement 1967-1974 (Washington, D.C.: Guildy McGraw Hill, 1974), pp. 290-291.

⁴Charles Curran, Christian Moral Theology Today, The Renewal of Moral Theology (Notre Dame, Indiana: Fides, 1966), p. 11f.; Charles Curran, ed., Absolutes in Moral Theology? (Washington, D. C.: Corpus Books, 1968), pp. 9-10; Charles Curran, A New Look at Christian Morality (Notre Dame, Indiana: Fides, 1968), esp. Chapters 1 and 3; Charles Curran, Transition and Tradition in Moral Theology (Notre Dame, Indiana: University of Notre Dame Press, 1979), esp. Chapter 1; Charles Curran, ed., with Richard McCormick, S.J., Readings in Moral Theology, No. 2, The Distinctiveness of Christian Ethics, "Is There a Catholic and/or Christian Ethics?" (Notre Dame, Indiana: University of Notre Dame Press, 1980), pp. 60f; Charles Curran, Moral Theology: A Continuing Journey (Notre Dame, Indiana: University of Notre Dame Press, 1982), esp. Part II, Chapter 3, "A Methodological Overview of Fundamental Moral Theology," and Chapter 4, "Three Methodological Issues in Moral Theology."

⁵Joseph Fletcher, Morals and Medicine (Boston: Beacon Hill Press, 1960), esp. the Preface; see also Daniel Jenkins, The Doctor's Profession (London, 1949), p. 16.

⁶Joseph Fletcher, Morals and Medicine (Princeton: Princeton University Press, 1954).

⁷S. Toulmin, "How Medicine Saved the Life of Ethics," Perspectives in Biology and Medicine, 25, No. 4 Summer, 1982, pp. 736-50.

⁸ Joseph Fletcher, Morals and Medicine, p. 215.

⁹ Ibid., p. xix.

¹⁰ Ibid., pp. 26-28.

¹¹ C. Curran, Moral Theology, 1982, p. 35.

¹² Cf. The fate of the Papal Commission on Birth Control of 1964 and particularly its effect on Drs. Andre Hellegers and Daniel Callahan.

¹³ New York University Law Review, Vol. 31, 1956, pp. 1189-1204.

¹⁴ Paul Ramsey, The Patient as Person, Explorations in Medical Ethics (New Haven, Conn.: Yale University Press, 1970).

¹⁵ Stanley Hauerwas, "Salvation and Health: Why Medicine Needs the Church," in E. Shelp, Theology and Bioethics, p. 213.

¹⁶ Cf. S. Toulmin, "How Medicine Saved the Life of Ethics," p. 749.

¹⁷ Gordon Kaufman, An Essay in Theological Method (Missoula, Montana: Scholars Press, 1975), p. ix.

¹⁸ A. MacIntyre, and S. Hauerwas, eds., Revisions: Changing Perspectives in Moral Philosophy (Notre Dame, Ind.: University of Notre Dame Press, 1983), p. 1.

¹⁹ The principle contributions are to be found in two volumes which were produced from Conferences held at the Hastings Center; H. T. Engelhardt, Jr., and D. Callahan, eds., The Foundations of Ethics and Its Relationship to Science, Vol. II, Knowledge, Value and Belief (Hastings-on-Hudson, New York: The Hastings Center, 1977); Vol. IV, Knowing and Valuing (Hastings-on-Hudson, New York: The Hastings Center, 1980).

²⁰ A. MacIntyre, "Can Medicine Dispense With a Theological Perspective on Human Nature?" Knowledge, Value and Belief, p. 35ff.; see also A. MacIntyre, "Theology, Ethics, and the Ethics of Medicine and Health Care . . .," Journal of Medicine and Philosophy, Vol. 4, 1979.

²¹A. MacIntyre, "A Rejoinder to a Rejoinder," Knowledge, Value and Belief, p. 76.

²²Ibid., pp. 77f.

²³Cf. the President's Commission Report, Deciding to Forego Life-Sustaining Treatment, Washington, D.C., U. S. Government Printing Office, 1983.

²⁴President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 2000 K Street, N.W., Suite 555, Washington, D. C. 20006.

²⁵In one list of Witnesses and Consultants published by the Commission there were names of 29 Theologians and 29 Philosophers.

²⁶E.g. testimony on the question: When is a person dead? included Rabbi David J. Bleich, Rabbi Moses Tendler, Father Kevin O'Rourke and Professor Paul Ramsey.

²⁷A. MacIntyre, After Virtue, second edition (Notre Dame, Indiana: University of Notre Dame Press, 1984).

²⁸Cf. Conway, "After MacIntyre," excerpts from a Philosophical Bestiary, Soundings, Vol. LXIX, No. 3, Fall, 1986, pp. 206-225; J. Stout, "Liberal Society and the Languages of Morals," Soundings, Vol. LXIX, No. 1-2, Spring/Summer, 1986, pp. 32-59.

²⁹James Gustafson, Ethics From a Theocentric Perspective, 2 Volumes (Chicago: University of Chicago Press, 1981 and 1984).

³⁰James Gustafson, "A Response to Critics," Journal of Religious Ethics, Vol. I, pp. 4-10.

³¹Ibid., pp. 81, 82.

³²Ibid., pp. 328ff.

³³J. Gustafson, Ethics From a Theocentric Perspective, I, pp. 8-81.

³⁴Ibid., p. 81, 90ff; II, 302f.

³⁵Ibid., I, pp. 81-82.

³⁶ We need note, as an example, the Roe vs. Wade decision of the U.S. Supreme Court did not settle the abortion debate.

³⁷ On other issues involved, see above Chapter 5.

³⁸ J. Gustafson, Ethics, Vol. I, pp. 1-3.

³⁹ Ibid., I, pp. 251ff.

⁴⁰ Ibid., II, p. 81.

⁴¹ A. Giddens, Social Theory and Modern Society (Cambridge, England: Polity Press, 1986), p. 141 paraphrasing Heidegger.

⁴² Augustine, Confessions in Basic Writings of Saint Augustine, Vol. I, W. J. Oakes, ed. (New York: Random House, 1948), Book XI, Chapters XIII-XVIII, pp. 191ff.

⁴³ It was not until theology was forced to turn from history and personal experience to nature as a clue to the "knowledge of God" that a change took place. Cf. R. Barbour, Issues in Science and Religion (London: SCM Press, 1966).

⁴⁴ E.g. a surgeon describing his experience of having the heart of a donor arrest before it was removed, remarked: "The patient nearly died before we could get the heart beating again!"

⁴⁵ P. Castelnuovo-Tedesco, "Organ Transplant, Body Image, Psychosis" Psychoanalytic Quarterly, Vol. 42, 1973, pp. 349-363; P. Castelnuovo-Tedesco, "Ego Vicissitudes in Response to Replacement of Body Parts," Psychoanalytic Quarterly, Vol. 47, 1978, pp. 381-397; P. Castelnuovo-Tedesco, "Transplantation -- Psychological Implications in Body Images," in N. Levy, ed., Psychophrenology, I., Psychological Factors in Hemodialysis and Transplantation (New York: Plenum, 1981), pp. 219-226.

⁴⁶ Bryan Jennett, High Technology Medicine (London: The Nuffield Provincial Hospital Trust, 1984), p. 4f.

⁴⁷ Cf. Roger Evans, et al., The National Heart Transplantation Study (Seattle, Washington: Battelle Human Affairs Research Center, 1985), 5 Volumes.

CHAPTER I

LOSING TIME

BN is 59 years old. He has been vigorous all of his life and currently works for a large electronics firm. He and his wife are childless and live in their own home in a suburb of the city where he is active in his local Catholic Parish, enjoys golf and is an outgoing and humorous person whose Irish descent is obvious. After a recent heart attack, Mr. N was referred to the Royal Victoria Hospital for evaluation as a potential candidate for a heart transplant. At the time of his admission, he was unstable and occupied a room in the CCU where he was closely monitored and had a Swan-Ganz catheter inserted. He required considerable support for his weak heart; and when I saw him, he was stable, conscious but quite subdued. He was oriented to time and place, was able to offer some critical comment on the skill of the Resident who put in the catheter, but gave the impression he was slow if not retarded mentally. There was only a vestige of his reputed sense of humor remaining. It was clear to him that his heart was finished, that the role which was left for medicine to perform was essentially making him as comfortable as possible until he died. There was, however, the

possibility that a heart transplant might provide him with a few more years of active life albeit with the small risk (10-15%) that this operation would be unsuccessful. In the event of his death, his wife would be well provided for by generous company insurance, and their house was paid for. She had a sister who was providing moral support for them, as well as a place to stay in Montreal which was convenient to the hospital. Everyone in the family support group agreed that a risk of a heart transplant was a better alternative than his present state of health.

Mr. N is representative¹ of the 125 patients who have been evaluated in the Heart Transplant Program at Royal Victoria Hospital since January 1985 and from what I have been able to discover of patients in similar programs elsewhere.² The story of how he and they got to a Transplant Centre is an important illustration of the complex processes that make up the practice of medicine today,³ and it is necessary to rehearse them in some detail in order to understand how this process of decision-making entails a moral and ethical structure.

A great deal of the time and energy (to say nothing of the money) of contemporary medicine is engaged in the practice of what Bryan Jennett has called "rescue."⁴ The main purpose of this rescue operation is to keep someone alive with the hope of allowing more traditional health care operations to take over. Rescue usually involves high technology. Heart transplantation is a good example of the

practice of rescue.⁵ While it may be debated whether or not technology has its main effect upon the mechanics of medicine or upon issues more secondary to its practice,⁶ it has produced an agenda for medical care which may not resemble that presented in the classical texts on the subject. The effective use of technology depends upon isolating the steps which make up medical activity and specifying the action involved in each.⁷ Jennett argues that the following four steps represent the setting from which high technology operates.⁸

Diagnosis depends on eliciting a history and examining the patient, sometimes supplemented by investigations; and then on processing all the information.

Prognosis depends on comparing the information about this individual patient with what is known about similar, previous patients who were managed in various ways.

Decisions have to be made about what to do for the patient as well as about what to tell the patient and his family.

Management is more complex, and is best analyzed by considering separately ends and means -- objectives and methods.

Before we provide a descriptive analysis of these principles in use, it will be useful to say a bit more about how this kind of activity fits into more traditional modes of medical care. To do this we must be reminded of current limits to

the scope and effectiveness of medicine. It is an elementary truism that about 70-80% of all human illness is self-limiting.⁹ The real practice of diagnosis is concerned with those conditions which make up the minority of medical conditions. Not all of this number are able to be identified and, of those which are, modern therapy is able to offer only a limited set of them an actual cure.¹⁰ Where cure is possible, it is rarely without risk of complication.¹¹ The vast majority of patients entering hospital is affected with progressive disease whose ultimate outcome cannot be influenced.¹² Quite possibly, it is misleading to describe the response to such patients as care even if this term is intended to be regarded as having a technical meaning. This is because incurable patients run a gamut which is different from those who are terminally ill, close to death and need comfort, good nursing and control of their pain in contrast to those who are chronically ill with a non life-threatening affliction which demands quite sophisticated palliation. Increasingly, a great deal of the medical activity centered in our hospitals is occupied with activities which are not appropriately described by either cure or care. We have referred to this practice briefly by the term rescue. Although Jennett¹³ has produced a partial characterization of this activity, we propose that it is quite crucial to spell out in some detail its implications -- theoretically, structurally, economically and ethically -- for the contemporary practice of medicine.

1. The situations which require intervention are life threatening although exactly how immediate the need is varies widely from emergency to elective.
2. The gauge of success is the postponement of death although it may make possible a cure somewhere down the line.
3. The limited perspective of a rescue operation can lead to a result which is a disaster from the perspective of quality of life.
4. Even if these interventions restore a satisfactory quality of life they frequently lead to a chronic dependence on medical care which is itself very expensive.
5. The treatments and the technology which support them are very expensive.
6. The number of patients which may benefit from a rescue operation is a small minority of those hospitalized, but may require a high proportion of a total health care budget.
7. There are no uniformly accepted standards for assessing the worth or value of these programs.
8. The equipment, buildings and personnel necessary for the successful operation of so-called rescue ventures are used also for more traditional cure, care and palliation activities. In the contemporary setting, they both supplement and compete with each other. It is often difficult, if

not impossible to sort out this relationship.

We can begin now to show how BN's acceptance for evaluation by a Heart Transplant Center places him in a slightly different position in the current health care scheme. The techniques employed in his protocol skew, to a degree which we hold is significant, not only his care but the very meaning of what has historically emerged as the role of medicine. This will emerge as his story unfolds and be developed as we take him through the four steps of the medical task which we have identified previously. His was one of the non-fatal heart attacks which occur every year in the Montreal area, of which approximately .05% result in leaving the victim with an end-stage condition.¹⁴ However, in 1985, only 12 with that condition were referred to RVH for evaluation. In 1986 the number was 16.¹⁵ Thus, there are obviously a number of factors and considerations which make it possible for someone to be transplanted successfully, and the details of these as they unfold reveal a great deal about the working of high technology medicine.

Since transplantation is performed at a limited number of designated centers, most of the patients get to these places through referrals. The principle referral agent is the cardiologist practicing in the community and staffing its hospitals. What he thinks of transplantation and the centers offering it is a major factor in determining the number and condition of the patients referred. In a survey of a small number of cardiologists which has sent patients for

evaluation to Royal Victoria,¹⁶ it was apparent that most had no direct contact with transplantation and were dependent upon professional meetings and journals for knowledge of the practice. Their motivation for sending on a patient was a function of their own sense of the responsibilities of the doctor/patient relationship and their desire to promote the best possible outcome for the individual patient. There was a recognition on the part of those referring that there was a selection process in place in each center, and that a wide range of medical and psycho-social criteria was employed in the course of evaluation. There seemed to be little awareness of the effects that technologies such as transplantation had upon the organization and function of hospitals offering it, or similar technologies. They were aware, however, that resource allocation was becoming a critical issue for those involved in health care, but made no attempt to reconcile this with their individual doctor/individual patient orientation.

BN presented two different problems to those responsible for his care. Most immediate was the need to stabilize his condition which was the result of a serious myocardial infarction suffered two months previous to his admission to the Royal Victoria Hospital. The other was to evaluate him as a potential candidate for a heart transplant. For someone in his condition, the evaluation process was not without serious risk¹⁷ because confirmation of his prognosis required a cardiac catheterization to rule out any alternative to

transplantation.¹⁸

High technology interventions are not for everyone who is close to death. The success rate of such activity seems to be a function of careful selection.¹⁹ At the same time this selection procedure helps to maintain some kind of reasonable balance between the number of recipients and the number of patients for whom the actual resources for the procedure are present.²⁰ In our case, this means the number of donor hearts. Selection for survival was developed by the Shumway team at Stanford which was the only group to maintain the practice of heart transplantation following the moratorium which emerged after the flurry of 1968 when nearly 100 operations were performed.²¹ The very idea of a moratorium on the practice is in itself instructive as to the nature of high technology and clinical research, and will be discussed when we look at some of the issues involved in technology assessment. Our immediate concern is the evolution of selection criteria as a means for allocating scarce resources.

The seminal experience in this activity was that used in the controversial attempts of 1961-1962 in Seattle, Washington to select candidates for dialysis when the potential candidates far exceeded the available supply of dialysis machines. Recent medical, ethical and social science literature contains a number of discussions of this experiment and the issues which emerged.²² Obviously the principal problem facing the selectors was how to come up with the best candidates for the limited places and what

criteria should be used to implement their work. All of the candidates were victims of end-stage renal disease (ESRD) and without dialysis had an expected life span of a few months at most. There was no alternative treatment available. Once on dialysis, the patient would remain dependent upon the machine until death ensued or the patient, knowing the result, requested dialysis to be terminated.²³ There was also the belief which had limited support from experience that certain people did better than others on dialysis and this difference appeared to be a function of what came to be termed psycho-social factors.²⁴ After the fact analysis of these psycho-social criteria showed that (at least in the Seattle program) they were typical characteristics associated with middle-class North American values and those selected or rejected by the team appeared to bear a striking resemblance or discordance with these middle class virtues.²⁵

The backlash to the Seattle experience was considerable and is significant for the way in which the emergent problems were faced.²⁶ In 1972 the United States Congress passed a special entitlement regulation under the Medicare Act which committed the federal government to pay the costs of dialysis for any patient requiring it.²⁷ It is also not without significance that original estimates for the annual cost of this program which was \$35 million had by 1985 jumped to an annual outlay of \$2,200,000,000.²⁸ The fundamental question as to whether selection for survival was both fair and/or necessary was by-passed. Because at that time the full impact.

of high technology upon the practice of medicine was not anticipated and it was assumed that the issue presented was a unique incident and not a foreboding of things to come.²⁹

A somewhat different problem confronted Dr. Norman Shumway and his team as they struggled to continue transplanting hearts after a general world-wide moratorium had emerged on this practice.³⁰ Initially, their problem was the general one of too few survivors, not a lack of resources. Shumway was of the opinion that the solution to this difficulty lay in the careful selection of candidates for the procedure.³¹ From this conviction grew the Stanford selection criteria which, although they concentrated upon medical factors, did not shy from employing a modicum of psychosocial standards as well. In the literature which has grown up around the Stanford selection criteria,³² too much attention has been given to that part of the process which concentrated upon weeding out, from among possible candidates, those least likely to survive, that is, upon the list of counterindications to transplantation. What has been missed is the scope and significance of the selection process which becomes an increasingly sophisticated form of risk calculation and decision analysis.³³ It originally meant to identify, with as much certainty as possible, those who are in immediate risk of death; and from this group, to select a few who are likely to outlive their projected demise -- keeping in mind the projected life expectancy of the transplant recipient. Implied, but not explicitly stated in this

attitude, is the notion that the closer any individual is to normal lifespan the less likely he is to be offered a transplant.³⁴ There has thus been a portentous alteration in the sense of need which is generated; because, in terms of the whole health care system, technology implies giving a heightened value to those it can help and thus demands that value in terms of cost be placed on every human participant in the system.³⁵

The actual unfolding of BN's history as a potential candidate for cardiac transplantation began on June 29, 1985 when he suffered an acute antero lateral massive infarct that hospitalized him for one month at a hospital in his community. His condition on discharge was such that he was referred to the transplant surgeon at Royal Victoria and seen as an outpatient on August 12. In the 6 weeks following his heart attack, his weight had dropped from 190 to 148 pounds. He was short of breath on exertion, etc., but otherwise, on the basis of history and physical examination, appeared to have no other systemic conditions which would preclude considering him for a transplant. The surgeon's provisional diagnosis was end-stage ischemic cardiomyopathy and he recommended to Mr. N and his wife that a detailed evaluation of his suitability for a heart transplant be instigated.

Before this study could be inaugurated BN had to be readmitted to hospital with symptoms of further deterioration in his already limited heart function; and on August 27, he was transferred to the Cardiac Care Unit of Royal Victoria

which is where our story began. Hemodynamic monitoring was established on admission together with inotropic support, and preparations were made for a cardiac catheterization as soon as his condition was reasonably stable. At this time, he was seen by the members of the transplant team representing the appropriate specialties which included infectious diseases, nephrology, psychiatry and social work. No contraindications for transplantation were detected and the team awaited the result of the catheterization. The report of the consultant was extremely terse and is worth quoting in its entirety.

"(This is the) most incredible lack of function I have ever seen on a live patient" and no attempt was made to visualize the coronary arteries. Shortly afterwards, on September 10, the team met and BN was placed on the waiting list for a heart transplant. On September 16 he underwent successful orthotopic heart transplantation and after two years remains well and active. He did accept early retirement from his employer, but his general level of activity is that of his pre-heart attack condition. He has stabilized his weight at 155 and in 1987 underwent an uncomplicated cholecystectomy.

Although Jennett's four steps³⁶ become compressed in the case of a patient such as BN they nonetheless remain visible in the events leading up to this transplant operation. They are, however, subsumed in the selection process which has emerged as necessary for the successful development of transplantation. Actually the four-step process occurs twice for every heart transplant candidate and we can see this in the

case of BN. The first diagnostic series aims at identifying as clearly as possible his condition, and developing from this a reliable prognosis which forms the basis for the first set of decisions and subsequent management. In the case of BN, the task was to determine whether he had end-stage heart disease, and the pathophysiologic process responsible. The possible causes of end-stage heart disease are numerous and include congenital and acquired valvular disease, myocarditis, coronary artery disease, pericardial disease and cardiomyopathy.³⁷ The two principal etiologic categories which are most common among candidates for heart transplantation are cardiomyopathy and coronary artery disease.³⁸

What these conditions have in common among this class of patient is their limited prognosis for survival. A patient becomes a potential candidate when his prognostic survival curve falls below expected survival with heart transplantation because he may reasonably be expected to have a longer life expectancy with transplantation.³⁹ At the same time, any surgical procedure besides transplantation, with a reasonable chance of improving the patient's prospects, should be considered favorably before transplantation.

How do you predict the future for end-stage cardiac patients and with what degree of certainty? The decision which rides on this prognosis is the one to "rule in" a patient as a potential candidate. This is normally the responsibility of the consulting cardiology members of the transplant team and their task is to amass the objective

evidence necessary to produce a reliable picture. Three kinds of information contribute to the prognosis:

1. Major clinical events in the course of the patient's illness which can include sudden death episodes, recurrent hospital admissions for congestive heart failure, and decomposition in face of minor viral illnesses are strongly suggestive for candidature as are severe symptoms such as marked disability, chronic hypotension, declining renal and hepatic function, and a tendency toward cardiac cachexia.
2. Noninvasively obtained information, including findings from physical examination indicating low cardiac output, cardiac failure, atrial and ventricular arrhythmias, muscle wasting, cardiac enlargement, pulmonary edema and/or effusions, hepatomegaly, pedal edema, is helpful and quite important in the patient who is on maximal medical therapy with digoxin, furosemide and afterload reduction with agents such as hydralazine or catopril.
3. Laboratory tests, which indicate prerenal azotemia, hyponatremia, hypoproteinemia, and hyperbilirubinemia are helpful indicators, as is abnormal cardiac functioning. A recent report suggests that the following parameters are significant: an ejection fraction of less than 20% has been associated with a negligible 2-year survival in patients having a dilated cardiomyopathy; and, in the same group, a left-ventricular

end-diastolic pressure of greater than 20mm Hg is associated with a 50% 2-year mortality with even higher deaths reported in patients with ischemic myopathies.⁴⁰

Having put together all this information does not of itself produce a prognosis because no precise formula exists for combining all these facts into a prognostic index or projected survival curve.⁴¹ Therefore, there is a strong element of judgment in whatever outcome is predicted and what decisions are made. A major influence on this judgment is how this prognosis stacks up against the known survival and quality of life data which is available for persons having a heart transplant.

Patients operated at Royal Victoria Hospital have about an 82% survival rate in the first year of transplantation and slightly less expectancy for 5 years, not taking into account the etiology of their heart disease.⁴² This is consistent with results which have been generated in other major institutions in Europe and North America.⁴³ Current experience with the use of cyclosporine, in the immunosuppressive protocols, suggests that the trend toward relatively small risks of death in years 2 through 5 is well established.⁴⁴ Of equal importance is the fact that there is a remarkable improvement in quality of life -- those patients with end-stage heart disease, with rehabilitation of over 90% of patients at 1 year -- most having attained NYHA functional class I status.⁴⁵

If we were to summarize the information currently available as to indicators for heart transplantation, it would appear that in not all cases is the evidence clear-cut but the survival and quality of life of those transplanted is quite clear.⁴⁶ Referral for evaluation has an important element of clinical judgment attached to it and this must be combined with judicious use of the contraindications to transplantation in order to rule out those who have conditions, in addition to end-stage heart disease, which could alter significantly the elements of risk. The second diagnostic series is concerned in exploring these "rule-out" elements which have come to be known world-wide as the Stanford criteria.⁴⁷

Contraindications to heart transplantation:

1. Advancing age; e.g. beyond the age (normally about 50⁴⁸) at which the individual begins to have diminished capacity to withstand postoperative complications.
2. Severe pulmonary hypertension as represented by a calculated vascular resistance above approximately 6 Wood units.⁴⁹
3. Irreversible and severe hepatic or renal dysfunction (because of the likelihood of early postoperative exacerbation and because of interference with immunosuppressive regimens).
4. Active systemic infection (because of the likelihood of exacerbation with initiation of immunosuppression).

5. Any other systemic disease likely to limit or preclude survival and rehabilitation after transplantation.⁵⁰
6. A history of some behavior pattern or psychiatric illness likely to interfere significantly with compliance with a disciplined medical regime (because a lifelong medical regimen, is necessary, requiring multiple drugs several times a day, with serious consequences in the event of their interruption or excessive consumption).⁵¹
7. Recent and unresolved pulmonary infarction or pulmonary roentgenographic evidence of abnormalities of an unclear etiology (because of the likelihood of pulmonary infection or its exacerbation with initiation of immunosuppression under such circumstances).⁵²
8. Insulin-requiring diabetes mellitus (because of exacerbation by long-term corticosteroid therapy).⁵³
9. Symptomatic or documented severe asymptomatic peripheral or cerebrovascular disease (because of observed accelerated progression in some patients after cardiac transplantation and on long-term corticosteroid treatment).⁵⁴
10. Acute peptic ulcer disease (because of the likelihood of early post-operative exacerbation).⁵⁵
11. The absence of adequate external psychosocial support for either short- or long-term bases (because such support is generally necessary during the inevitable waxing and waning of the clinical status of the patient and for adherence to the lifelong medical regimen).⁵⁶

In Jennett's terms, the decision and management which concluded this second diagnostic series is crucial for sustaining transplantation. On its basis, in the pre-cyclosporin era, Stanford achieved a 65% survival rate for one year and over 50% after five years⁵⁷; and these results were soon replicated by other centers using the Stanford criteria.⁵⁸ We have already noted that increasing experience among several centers has led to a modification of a number of these original requirements but there has not as yet been a significant change in the principles which underlay their use. Moreover, this aspect of candidate selection, known as the Stanford criteria, has come to dominate the literature on the subject, coupled as it has been with the success of heart transplantation. One of the interesting sideplays of this success story has been its effect upon the resource allocation questions which had originally plagued the introduction of dialysis and now has come back to haunt heart transplantation.⁵⁹ There was not only the general problem of cost, which initially with heart transplantation made it the most expensive procedure in use.⁶⁰ There was also the specific issue raised by the restricted supply of heart donors,⁶¹ and the matter as to candidates for transplantation offered the most potential for survival,⁶² as well as the order of priority a person should have on the waiting list for a heart.⁶³ It has made heart transplantation the most studied and analyzed procedure in the medical field,⁶⁴ while at the same time considerable reluctance has persisted

towards employing this data to alter the scope and structure of public policy.⁶⁵ It is as if no one wishes to acknowledge the radical implications of these health care innovations.

It is our contention that these questions presented by this high technology are ethical. We have introduced the principal factors in the selection of candidates for transplantation in order to ask how this series of developments has been viewed by those concerned with ethical issues as they effect recipients. The initial analysis saw heart transplantation as simply another new procedure and was concerned to protect the original patients in the same way that candidates for any new and experimental procedure are now covered.⁶⁶ The chief article here is that which relates to the requirements of informed consent and there was a struggle to appreciate all of the elements of transplantation which needed to enter into the process of becoming informed as a patient, albeit many of these factors touched upon issues which were still taboo in many circles, such as the need to tell a patient he was dying.⁶⁷ Nonetheless, a good case can be made for the view that transplantation was not so different from the

sense in which medicine, even in its less heroic, more everyday activities, is always committed to intervening in ultimate problems of the human condition. Its latent existential functions concern birth, life, physical and psychic suffering, disability and death. In the practice of modern medicine, the physician ushers life in and ushers it out. Through contraception and abortion, he helps determine whether or not human lives will come into existence. He pronounces death. He diagnoses human malaise. He administers to those deemed physically or psychologically ill. And he

tries to forestall as well as to cure the forms of anguish -- labeled sickness -- with which he has been trained to deal. From this perspective, organ transplantation and chronic hemodialysis are merely two of the more recent techniques that medicine has devised to sustain life and fend off death.⁶⁸

The point which we would emphasize here is that ethical issues are thus often invisible in the cultural and factual setting of medical practice.⁶⁹ From this it follows that the ethical norms which are used to govern these practices are likewise often unexamined. The question we would raise is whether or not the general depiction of medicine just quoted is adequate to cover all that is involved in high technology medicine. Are other considerations conceivable? It is our view that high technology medicine has drastically altered the rules of the game and reasons for this belief will be developed in the course of our presentation. However, there is also, as Fox and Swazey show, the role played in the development of transplantation by the specific practices of clinical research and its interest in therapeutic innovation. From this point of view the growth of heart transplantation illuminates a number of crucial characteristics of contemporary medicine:

We are concerned with a few of the ethical questions of therapeutic innovation raised by the application of new treatments to sick people. These are initial trials, carried out in human patients, of drugs or operations that may benefit the subject. This is the largest single category of medical experimentation -- if that is a suitable term for therapeutic innovation -- currently practical at the clinical level.⁷⁰

I do object slightly to the idea that cardiac transplantation is human experimentation. From our point of view as physicians, it should be considered clinical investigation. [And from the recipient's

perspective] these are patients who are desperate, who are staring death in the face, and for whom there is at the moment no other possible treatment.⁷¹

A point I think we mustn't stress so much [in discussing candidates for heart transplants] is ... that the patient must have a will to live. I think many a man in the terminal stages of heart failure ... who is really sick and has a poor blood supply to the brain from poor cardiac output would say: "Oh please leave me alone, I want to die." But I don't think that the patient can decide whether he wants to die or not. I think that as doctors our duty is to give the patient all the therapy and all the treatment that is available to us.⁷²

The clinical investigator has special significance for ethical developments in transplantation for he has a particular attachment to the human and medical aspects of need as motivation for his work. The physician-investigator emerges as a rather special person:

For all its intellectual, professional, and humanitarian gratifications, the role of research physician is accompanied by characteristic problems and stresses. [In particular they are] problems of uncertainty such a physician encounters, resulting from limitations in medical knowledge and practice at a given time. To these may be added those uncertainties that are artifacts of the inability of any physician personally to command all available medical knowledge and skill. Furthermore, the research physician deliberately works in the realm of the uncertain, focusing on these questions which medicine still has not answered, seeking to make some headway with their solution.⁷³

They must be ready to consider medical science as involving:

A process of therapeutic innovation which generally progresses from animal experiments to clinical trials with terminally ill patients beyond conventional therapeutic help, to the use of the treatment on less and less critically ill patients.⁷⁴

However, to appreciate what this means it is necessary to note that their method goes beyond that of the ordinary physician:

In order to evaluate what constitutes the justifiable use of a new medical procedure and appraise "success" and "failure," physicians characteristically make what Joseph Fletcher has termed "mathematicated decisions" based upon a "statistical mortality." They estimate and express in terms of probabilities and percentages the differential diagnosis of a disease, and its course under different circumstances, especially its prognosis to alternative treatments. This way of reasoning is not peculiar to the clinical investigator; rather it is inherent in all medical practice.⁷⁵

It may be instructive to show how they are moved by a singular devotion to both human need and mathematical probability:

We have noticed that after his first four valvulectomies Cutler acknowledged that a 75 percent mortality rate is "alarming," but maintained that in terms of each case it is not "disastrous," and affirmed that his results must be judged in comparison with other pioneering surgical efforts -- mortality rates of 65 to 81 percent were long common in surgery "of such a relatively simple field as that of the stomach." Similarly, in his "Final Report" of 1929, Cutler insisted that "the mortality figures (90 Percent) alone should not deter further investigation since they are to be expected in the opening up of any new field of surgical endeavor."⁷⁶

and so what emerges is a concept of "statistical mortality" which allows rationalizing the use of this new treatment for critically ill patients. In these cases it is argued that if all available conventional therapies have been tried unsuccessfully, then without the new treatment the patient would die anyway.⁷⁷ Their conclusion while correct fails to take into account the more exposed, tenuous and privileged position occupied by the clinical investigator in the practice of medicine as may be illustrated by the absence of malpractice criteria for their work.⁷⁸ It may also be argued that they have moved beyond the charted boundary of the then current ethical conceptualizations.. This has led

us to believe that an altered concept of time becomes important for appreciating the ethical issues which emerge from these new developments in high technology medicine.⁷⁹

And so a somewhat transformed ethical perspective begins to emerge if transplantation is viewed as a response to the end-stage condition of a disease process in a particular patient. A candidate for a transplant knowing that death is imminent, is expected to put in perspective the risk involved in the transplant operation. There is the legitimate question as to how free consent given under these extreme circumstances might be.⁸⁰ Would anyone actually choose death as the preferable alternative to an operation with risk that promised reasonable quality of life in return? At the base of this question is the belief that a person has the right to determine his life course even in the face of what traditionally had been the givens of nature and its creator.⁸¹ However, what the perspective of rights in this rationale also suggests is that an individual has the right to claim whatever lies in the power of another to give.⁸² Once again, the historical factors which make possible this scenario of options needs to be made explicit.

There is the fact that the work of science has normally fallen outside of the purview of social cost and desirability⁸³ and medical need is often not the generative principle directly behind the creation of a medical technology.⁸⁴ It may be related to a fortuitous coming together of basic science research which makes something "possible."⁸⁵

The application comes so quickly on the heels of the basic science that there is not time or structure available for the necessary social evaluation. With this difference in the social function between science and technology, how does the doctrine of informed consent offer protection to a patient contemplating a high technology procedure? It does appear to this writer that we have tended to underestimate the ability of technology to make our standards of judgment obsolete.⁸⁶ Technology forces society to make judgment about what will be good or bad for it and its individual members on the basis of very imperfect information. It creates a reciprocal relationship between the good of both which must be projected into the future. This has the effect of reducing the protective power of informed consent in the technological age.

Medically speaking, there are additional problems with informed consent as it applies to at least some of the heart transplant candidates. This was alluded to by Christian Barnard above.⁸⁷ Mention has been made that BN, while clearly honoring the requirement that he be oriented to time and place, often gave the impression that he was mentally slow with impaired comprehension. Was this condition a temporary result of poor perfusion related to his gravely impaired heart function or was it indicative of a non-reversible condition which could make him a poor shadow of his former self should he survive surgery?⁸⁸ How should the quality of his consent be understood?⁸⁹ Under many circumstances it could be argued that it might be prudent to obtain a proxy consent in order

that the patient's best interest be as protected as much as possible.⁹⁰ While not wishing to downplay the importance of established precedents which have filled out the doctrines of consent and best interest, it does appear that under these conditions they fall short of the demands for protection posed by the presence of high technology. Some new forms of regulation might be required:

1. The increasing fragmentation of health care services by technology into a series of successful procedures affecting a relatively small number of those suffering from a given disease may make individual judgment a relatively minor mode of protecting personal rights, because the major decision will be whether to offer the service. We have used the term "social warrant"⁹¹ to indicate the general desirability of a particular technology and by this it is intended to show that its social effect and cost has been weighed and approved because there is already common agreement as to the existence of medical need.⁹² That is to say the first line of consent has to come from the community since the development of a given technology is so expensive and complex, it will not be possible for anyone to afford it, even if a few persons exist who could find the money to pay for the procedure on themselves once it has been developed.⁹³ In addition, having social warrant implies that it is the considered

judgment of society at large that it is appropriate to offer a human being such treatment, even if his own appreciation of it may be impaired. It is important also to suggest that the role of the treating physician, as the one offering a service, will be modified precisely because he alone cannot be totally responsible for the medical act although his own action may still be subject to the traditional scrutiny. The conflict between the role of physician investigator and advocate and protector of the individual patient is quite keen:

Being a clinical investigator has its problems. A lot of the research you do is of no benefit to patients, and there's a real possibility that you can do them harm. So in order to do research you've got to close your eyes to some extent, or at least take calculated risks with the patients on whom you run the experiments Still you never attain the ideal research You rarely get to the basis of the problem you're investigating, because it's tough and go all along the way with these patients. Their care and welfare have to be taken into consideration So, you usually end up by compromising your research goals and standards.⁹⁴

2. The principle of informed consent may have a more restricted but crucial application in the development of procedures and the experimentation on human subjects which will be necessary for their perfection. The data available on early work in heart transplantation or in the development of the artificial heart suggest that major deficiencies existed in the protocols and information given to prospective patients such as Louis Washkansky⁹⁵ or

Barney Clark⁹⁶ and there is little cause for joy in the aftermath of the Baby Fae case, in which very elementary requirements of consent were violated.⁹⁷ In the latter affair it seems not unreasonable to suggest that a more formal social warrant for Xenograft experiments on human beings needs to be in place than is presently the case and the same argument can be made historically about the development of the artificial heart.⁹⁸ Something like the concept of "social warrant" may have to be extended to the developmental aspects of technology research.

3. This leads to the more general question of how a balance between the creativity of research and development and the overall responsibilities of a health care system may be achieved. This topic will be discussed in detail in Chapter 2; however, the major point to be made here is that the protective potential of the doctrine of informed consent is extremely limited, given the dynamics of technological development fueled by unlimited fires of human need.

In introducing the principle of social warrant, we have alluded to the possibility that alternative structures for ethical evaluation may be in order and have tried to show the need for these new forms by noting the significant limitations to the protection offered by informed consent. We shall now enlarge upon this contention. The issue is really how do we

analyze the current effort made to rationalize the development and use of high technology in medicine as it appears in heart transplantation.

Footnotes to Chapter I

¹The writer has been a participant observer on the Heart Transplant team since June 1985 and has interviewed most of the patients referred for evaluation in preparation for this dissertation.

²Interviews also were conducted in Columbia-Presbyterian Hospital in New York as well as Harefield and Papworth in the United Kingdom.

³B. Jennett, High Technology Medicine, Benefits and Burdens, The Nuffield Provincial Hospitals Trust, London, 1984, p. 5.

⁴Ibid., p. 4.

⁵Ibid., p. 4.

⁶Ibid., p. 2; see also A. Reiman, "Technology Costs and Evaluation," NEJM, Vol. 301, No. 26, pp. 1445-5 198; H. Fineberg, and H. Hiatt, "Evaluation of Medical Practices -- The Case for Technology Assessment," NEJM, Vol. 301, No. 20, 198; A. Donabedian, "The Quality of Medical Care," in S. J. Williams, Issues in Health Services (New York: Wiley, 1980), pp. 276ff.

⁷B. Jennett, High Technology Medicine, p. 3.

⁸Ibid., p. 3.

⁹S. Fletcher, "Medical Care in Teaching Hospitals: How Good Is It?" McGill Medical Journal, Volume 44, Fall-Winter, 1975, p. 8.

¹⁰J. and S. McKinley, "The Questionable Contribution of Medical Measures to the Decline of Morality in the United States in the Twentieth Century," in Milbank Memorial Fund Quarterly/Health and Society, Vol. No. 55(3): 405-428, 1977.

¹¹P. F. D'Arcy and J. P. Griffin, Iatrogenic Diseases (London/New York: Oxford University Press, 1972), p. 4.

¹²B. Jennett, High Technology Medicine, p. 4.

¹³Ibid., p. 4.

¹⁴This is a rough estimate based upon comparison of Canadian and British statistics for the incidence of Acute Myocardial Infarction. In numbers, it would be more than 100.

¹⁵From records of RVH Heart Transplant Team.

¹⁶See Appendix, Study of Cardiologists.

¹⁷Unlike other forms of treatment for end-stage heart disease, evaluation for heart transplantation requires a number of invasive procedures which might well be foregone in a seriously ill patient; cf. P. B. Beeson, W. McDermott and J. B. Cecil, Textbook of Medicine, 15th ed. (Philadelphia: W. B. Saunders, 1979), p. 1078.

¹⁸See the discussion of criteria below,

¹⁹See below pages 12ff.

²⁰Cf. A. Caplan, "Equity in the selection of recipients for cardiac transplants," Circulation, Vol. 75, No. 1, 1-306, January, 1987, pp. 14-15.

²¹R. Fox and J. Swazey, The Courage to Fail, 2nd ed. (Chicago: University of Chicago Press, 1978), pp. 108ff.

²²Ibid., especially Part 3; A. Caplan, "Kidneys, Ethics and Politics: Policy Lessons of the ESRD Experience," Journal of Health Politics, Policy and Law, Vol. 6, No. 3, Fall 1981, pp. 488ff; The National Heart Transplantation Study, final report, Vol. 1, Chapter 2 (Seattle: Battelle Human Affairs Research Centers, 1984).

²³R. Fox and J. Swazey, The Courage to Fail, p. 262.

²⁴Ibid., p. 237. Although the methods employed in Seattle have come under fire, a spate of articles on the subject of the psychosocial effects of dialysis indicate how pertinent the issue is.; cf. B. Beard and T. Sampson, "Denial and Objectivity in Hemodialysis Patients," in N. Levy (ed.), Psychonephrology, I (New York: Plenum Books, 1981, pp. 169-75; D. C. Buchanan, "Psychotherapeutic Intervention in The Kidney Transplant Service," in N. Levy (ed.), Psychonephrology, I, pp. 265-277; H. J. Burton, et al., "The Relationship of Depression to Survival in Chronic Renal Failure," in Psychosomatic Medicine, Vol. 48, No. 3/4, March, April 1986,

pp. 261-266; A. K. DeNour, "Prediction of Adjustment to Chronic Hemodialysis," in N. Levy (ed.), Psychonephrology I, pp. 117-132; A. Drees and E. Gallagher, "Hemodialysis, Rehabilitation and Psychological Support," in N. Levy (ed.), Psychonephrology, I, pp. 133-146; H. Freyberger, "Consultation -- Liaison in a Renal Transplant Unit," in N. Levy, Psychonephrology, I, pp. 255-263; R. A. Gutman, et al., "Physical Activity and Employment Status of Patients on Maintenance Dialysis," New England Journal of Medicine, Vol. 304, No. 6, February 5, 1981, pp. 309-313; R. Simmons, "Long-Term Reactions of Renal Recipients and Donors," in N. Levy (ed.), Psychonephrology, I, 275-287; J. Steinberg, et al., "Psychological Factors Affecting Acceptance or Rejection of Kidney Transplants," in N. Levy (ed.), Psychonephrology, I, pp. 185-193.

²⁵ R. Fox and J. Swazey, The Courage to Fail, p. 232; A. Caplan, "Obtaining and Allocation Organs for Transplantation," Manuscript, pp. 10-11.

²⁶ R. Fox and J. Swazey, The Courage to Fail, p. 345; A. Jonsen, National Heart Transplantation Study, Seattle, 184 Chapter 36-1; see also Chapter 2.

²⁷ Public Law 92-603 which was part of the 1972 amendment to the Social Security Act.

²⁸ From U. S. Medicare ESRD payments as of December 31, 1987.

²⁹ Arthur Caplan, "Kidneys, Ethics and Politics: Policy Lessons of the ESRD Experience," pp. 489-91.

³⁰ R. Fox and J. Swazey, The Courage to Fail, pp. 126f.

³¹ Ibid., pp. 312ff.

³² Federal Register 46 (14): 7072, 1981 printed as part of J. Copeland et al., "Selection of Patients for Cardiac Transplantation," Circulation, Vol. 75, No. 1, January 1987, p. 5.

³³ J. Copeland et al., "Selection of Patients for Cardiac Transplantation," 1987, p. 3.

³⁴ Ibid., p. 4.

³⁵ A. Caplan, "Equity in the Selection of Recipients for Cardiac Transplants," 1987, p. 12.

³⁶See page 3.

³⁷J. Copeland et al., "Selection of Patients for Cardiac Transplantation," p. 2.

³⁸At Royal Victoria Hospital they account for 52% of all heart transplant recipients. J. Copeland, et al., "Selection of Patients for Cardiac Transplantation," p. 2 indicate that each category supplies about 45% of their recipients.

³⁹J. Copeland et al., "Selection of Patients for Cardiac Transplantation," p. 2.

⁴⁰From J. Copeland et al., "Selection of Patients for Cardiac Transplantation," p. 3.

⁴¹Ibid., p. 3.

⁴²As of January 1, 1988, 48 patients have been transplanted; 39 are alive at this writing. All deaths but one have occurred within the first 3 months. The lone exception died 15 months after receiving a graft.

⁴³National Heart Transplantation Study, 1984, pp. 31-1; Costs and Benefits of the Heart Transplant Programmes at Harefield and Papworth Hospitals, Department of Health and Social Security, HMSO, Research Report No. 12, London, 1985, pp. 69ff; J. Copeland et al., "Selection of Patients for Cardiac Transplantation," p. 3.

⁴⁴Cf. B. Kahan, "Immunosuppressive Therapy With Cyclosporine for Cardiac Transplantation," Circulation, Vol. 75, No. 1; January 1987, p. 40; M. Slapak, "Triple and Quadruple Immunosuppressive Therapy in Organ Transplantation," The Lancet, Vol. , October 24, 1987, pp. 958-960; a cautionary note is found in "Cyclosporine for Ever?" The Lancet, Vol. 1 for 1086, No. 8748, February 22, 1986, pp. 419-420.

⁴⁵J. Copeland et al., "Selection of Patients for Cardiac Transplantation," p. 3. At RVH the figure is 90%.

⁴⁶Ibid., p. 3; The National Heart Transplantation Study, Chapters 23-26; Costs and Benefits of the Heart Transplant Programmes at Harefield and Papworth Hospitals, Chapters 9 and 10.

47 Federal Register 46(14): 7072, 1981. These represent the criteria developed in the pre-cyclosporine era largely because of the efforts at Stanford.

48 Now advanced to cover those as old as 65. Such is the practice at Royal Victoria Hospital.

49 Those patients who are otherwise acceptable as candidates, except for the elevated pulmonary systolic pressure, are frequently accepted into the heart and lung transplant program.

50 With increasing experience in postoperative management these criteria are viewed as much less absolute.

51 This is open to a wide interpretation, with a tendency to be open to anyone showing evidence of satisfactory response to treatment.

52 This is at most a temporary contraindication which may be waived if the patient is not likely to survive without an immediate transplant.

53 No longer a contraindication.

54 This remains a relative contraindication, and unless surgical correction is possible, the team at RVH will likely refuse the candidate.

55 Of some concern to most centers but rarely more than a temporary contraindication.

56 At RVH, this is a subject for intense debate among the team. Our experience is that it is not a contraindication but is an almost sure indication that the post-operative career of the patient will pose problems both psycho-socially and medically. Cf. F. Mai, "Graft and Donor Denial in Heart Transplant Patients," American Journal of Psychiatry, Vol. 143, No. 9 September 1986, pp. 1159-1161; R. Simmons et al., "Transplantation and Changing Norms: Cultural Lag and Ethical Ambiguities," in Gift of Life: The Social and Psychological Impact of Organ Transplantation (New York: John Wiley and Son, 1983), pp. 9-13; C. Callender, "Legal and Ethical Issues Surrounding Transplantation: The Transplant Team Perspective," in D. Cowan et al. (eds.), Human Organ Transplantation (Ann Arbor, Michigan: Health Administration Press, 1987), pp. 42-51; Virginia O'Brien, "Psychological and Social Aspects of Heart Transplantation," Heart Transplantation, Vol. IV, No. 2,

February, 1985, pp. 229-231; M. J. McAleer, et al., "Psychological Aspects of Heart Transplantation," Heart Transplantation, Vol. IV, No. 2, February 1985, pp. 232-233; National Heart Transplantation Study, Chapter 9.

⁵⁷R. Fox and J. Swazey, The Courage to Fail, p. 315.

⁵⁸Ibid., p. 315.

⁵⁹Ibid., p. 343; The National Heart Transplantation Study, 1-7; A. Caplan, "What are the Morals of Our Treatment of Renal Failure?" in L. J. Hodges (ed.), Social Responsibility: Journalism, Law and Medicine (Richmond, Virginia: Washington and Lee University Press, 1980), pp. 32-50; A. Caplan, "Kidneys, Ethics and Politics: Policy Lessons of the ESRD Experience," Journal of Health Politics, Policy and Law, Vol. 6, No. 3, Fall 1981, pp. 488-503.

⁶⁰G. Annas, "Regulating Heart and Liver Transplants in Massachusetts: An Overview of the Report of The Task Force on Organ Transplantation," in Law, Medicine and Health Care, Vol. 13, No. 1, February 1986, p. 6; R. W. Evans, "Economic and Social Costs of Heart Transplantation," Heart Transplantation, Vol. 1, No. 3, May 1982, p. 250; The National Heart Transplantation Study, 1-6.

⁶¹L. Resnekov, "A Research Endeavor or an Accepted Form of Treatment," Heart Transplantation, Vol. 1, No. 2, February 1982, p. 126; A. Caplan, "Equity in the Selection of Recipients for Cardiac Transplants," pp. 10ff; A. Jonsen, "Selection of Recipients for Cardiac Transplantation," The National Heart Transplantation Study, Chapter 36.

⁶²K. Merrikin, et al., "Patient Selection for Heart Transplantation: When Is a Discriminating Choice Discrimination?" Journal of Health Politics, Policy and Law, Vol. 10, No. 1, Spring 1985, p. 7; J. Robertson, "Supply and Distribution of Hearts for Transplantation: Legal, Ethical and Policy Issues," Circulation, Vol. 75, No. 1, January 1987, pp. 81-82.

⁶³Initially there were only one or two persons waiting for a heart transplant; the development of multi centers each with a waiting list has greatly changed the scene. Cf. A. Caplan, "Equity in the Selection of Recipients for Cardiac Transplants," Circulation, Vol. 75, No. 1, January 1987, p. 17; T. Starzl et al., "A Multifactorial System for Equitable Selection of Cadaver Kidney Recipients," JAMA, Vol. 257, No. 22, June 12, 1987, pp. 3073-3075.

⁶⁴ National Heart Transplantation Study, 1-2.

⁶⁵ Ibid., 1-2.

⁶⁶ R. Fox and J. Swazey, The Courage to Fail, Chapter 3.

⁶⁷ For a discussion of the relationship of transplantation to attitudes towards death, see Fox and Swazey, The Courage to Fail, p. 377; on the subject of truth-telling, see S. Bok, Lying (New York: Pantheon, 1975); C. Lidz et al., "Barriers to Informed Consent," Annals of Internal Medicine, Vol. 99, No. 4, October 1983, pp. 539-543.

⁶⁸ R. Fox and J. Swazey, The Courage to Fail, p. 376.

⁶⁹ Ibid., p. 376.

⁷⁰ F. D. Moore, "Therapeutic Innovation: Ethical Boundaries in the Initial Clinical Trial with New Drugs and Surgical Procedures," in P. Freund (ed.), Experimentation with Human Subjects (New York: George Braziller, 1970), pp. 358-378, as quoted by Fox and Swazey, The Courage to Fail, p. 61.

⁷¹ N. E. Shumway, et al., "Cardiac Homotransplantation in Man," Transplantation Proceedings, Vol. 1, March 1969, p. 187, as quoted by Fox and Swazey, The Courage to Fail, p. 61.

⁷² C. Barnard, in H. A. Shapiro (ed.), Experience With Human Heart Transplantation. Proceedings of the Cape Town Heart Transplantation Symposium, 1968 (New York: Appleton-Century Crofts, 1969), pp. 266-67, in Fox and Swazey, The Courage to Fail, pp. 61-2.

⁷³ J. P. Swazey and R. C. Fox, "The Clinical Moratorium," in R. C. Fox, Essays in Medical Sociology (New York: Wiley, 1979), pp. 350-351, in The National Heart Transplantation Study, 42-6-7.

⁷⁴ Ibid., 347.

⁷⁵ R. Fox and J. Swazey, The Courage to Fail, p. 66.

⁷⁶ J. P. Swazey and R. C. Fox, "The Clinical Moratorium," in The National Heart Transplantation Study, 42-10.

⁷⁷ R. Fox and J. Swazey, The Courage to Fail, p. 66.

⁷⁸D. Cowan, "Regulation of Medical Practice," in Human Organ Transplantation, Societal, Medical-Legal, Regulatory, and Reimbursement Issues, D. Cowan et al. (eds.) (Ann Arbor, Michigan: Health Administration Press, 1987), pp. 105-125; however, see also the discussion of the Karp case, Fox and Swazey, The Courage to Fail, pp. 135ff; T. Overcast et al., "Malpractice Issues in Heart Transplantation," The Amer. Journal of Law and Medicine, Vol. 10, No. 4, 1984, 363-395.

⁷⁹See above p. 14; also Fox and Swazey, The Courage to Fail, p. 377.

⁸⁰A. Jonsen, National Heart Transplantation Study, 37-11; M. Somerville, "'Procurement' vs. 'Donation' -- Access to Tissues and Organs for Transplantation: Should 'Contracting Out' Legislation be Adopted?" Transplantation Proceedings, Vol. XVII, No. 6, Supplement 4, December 1986, p. 66.

⁸¹Massachusetts Task Force Report: Law, Medicine and Health Care, Vol. 13, No. 8, 1985; A. Jonsen, The National Heart Transplantation Study, 37-14f.

⁸²A. Jonsen, The National Heart Transplantation, 38-1f.

⁸³Hans Jonas, The Imperative of Responsibility (Chicago, Ill.: University of Chicago Press, 1984), pp. 6f; J. M. Thomas, Ethics and Technoculture (Lanham, New York: University Press of America, 1987).

⁸⁴A. Caplan, "The High Cost of Technological Development: A Caveat for Policymakers," New Options, New Dilemmas, A. S. Allen (ed.) (Lexington, Mass.: Lexington Books, 1986), p. 80ff and esp. p. 91.

⁸⁵H. H. Hiatt, M.D. America's Health in the Balance (New York: Harper and Row, 1987), pp. 155-6.

⁸⁶A. Caplan, "How Should Values Count in the Allocation of New Technologies in Health Care?" In Search of Equity, Health Needs and the Health Care System, R. Bayer, A. Caplan and N. Daniels (eds.) (New York: Plenum Press, 1985); A. Caplan, "Economic and Social Issues," New Options, New Dilemmas; R. M. Veatch, "Justice and Valuing Lives," Life Span: Values and Life-Extending Technologies (New York: Harper and Row, 1979).

⁸⁷See note 72.

⁸⁸There was really no way for the Team to know with any degree of certainty. It relied upon the clinical experience of the surgeon who had seen similar cases.

⁸⁹The Team emphasized the education of the patient and his family, feeling that the cumulative effect of its work would lead to a better understanding of the implications of his decision.

⁹⁰This is absolutely necessary in situations in which the patient is too ill to comprehend what choices are being offered.

⁹¹Since using this term, I have found a somewhat similar concept introduced by George Annas, "Death and the Magic Machine: Informed Consent to the Artificial Heart," Western New England Law Review, Vol. p, Issue 1, 1987, pp. 89f.

⁹²In the case of the existence of End-Stage Heart Disease for which no other medical treatment exists.

⁹³E.g. the development costs for the Artificial Heart, which have come from U.S. Government funds, are already in the multi-million dollar range.

⁹⁴R. C. Fox, Experiment Perilous (Glencoe, Illinois: Free Press, 1959), pp. 55-56.

⁹⁵J. Katz, "Patient Autonomy and the Process of Informed Consent," in After Barney Clark, M. Shaw (ed.) (Austin, Texas: University of Texas Press, 1984), p. 12 and p. 14.

⁹⁶The issues here are more complex, but there is some cause for concern over the ambiguity surrounding the "turning off" of the device; cf. M. Shaw, After Barney Clark.

⁹⁷Cf. The N.I.H. Report of its Review of the Baby Fae Case, " IRB, Vol. 8, March/April 1986.

⁹⁸G. Annas, "Death and the Magic Machine," pp. 11ff; L. Tancredi and A. J. Barsky, "Technology and Health Care Decision Making -- Conceptualizing the Process for Public Informed Consent," Medical Care, Vol. 12, No. 10, October 1974, pp. 845-859.

CHAPTER II

MAKING TIME

... "other considerations" -- the need to be seen to do something, continuation of past practices, the desire to generate earnings or display professional prowess, possibly above all the need to act in unsatisfactory situations -- seem to underly a remarkably large part of health policy as well as health care services. While formal project evaluation has made enormous strides in the past decade in both methodology and range of application, there remains a great gulf between what is learned from such analysis and what is done.

Not least, of course, this is due to the fact that such analyses are threatening to clinicians, administrators, bureaucrats, and politicians alike. They call into question existing patterns of activity and raise embarrassing questions, not only from outsiders, but in one's own mind. Accordingly, while there are some clear cases -- hypertension screening for example -- in which formal evaluations have given clear-cut answers that are translated into clinical practice, more generally the results of project evaluation, at least in health care, are ignored or resisted.

And a large proportion of health care interventions are innocent of any formal or scientific evaluation at all, not just of efficiency, but even of efficacy. It is remarkable, and maybe without parallel in human activity, that so much effort and resources are devoted through public or private channels to health care whose effectiveness has not been conclusively demonstrated, at least for the purposes claimed, either in the setting of application or at all. Odd.¹

The very idea that medicine has sufficient power over the ravages of disease so that this effect should be subject to measurement for efficacy and efficiency is quite new and offers some insight as to the effects of basic science research and technological innovation in our time. It is

important to document the progression of these effects in order to be able to see the kinds of change which have been brought about by the recent introduction of high technology into the practice of medicine.

A review of alterations which have appeared as significant for medical practice in the past two centuries will give some notion as to the rate and type of transformation which they have brought about. This would appear to be an uncomplicated exercise; however, this survey will reveal considerable controversy about what has happened, for what reasons and with what significance for the current state of medical practice. Both the interpreters selected, Stanley J. Reiser and Eric Cassell, are sympathetic to the contribution of high technology to medicine; but, as we shall see, differ markedly in their depiction of its effect upon medical practice and the problems which it generates. We begin with Reiser:

A technological dominance of health care has developed in the twentieth century, although some of its key ideological and pragmatic goals reach back in time to the Renaissance and the scientific revolution, which transformed the reigning view of medicine, that had been shaped by the ancient Greeks.²

These changes show a significant relationship between developments in the area of ideas and that of machines. Vesalius, in 1643, challenged the medieval perspective on ancient authority (in this case the structure of the human anatomy as put forward by Galen C. E. 130-200) by insisting that nature must be studied by direct encounter rather than memorizing existing texts. His ideas found a friendly audience though

it is important for us to recognize in Reiser's words that:

The metaphor of dissection, of separating wholes into parts in order to understand their working, became a central if not the most significant method of exploration as the scientific revolution took hold.

It seems apparent that the use of dissection produced changes in understanding best conveyed by the concept of metaphor.

Then Robert Hooke described his examination of cork in 1665 observing that living matter seemed to be composed of cells.

This ocular technology moved us significantly beyond the metaphor of dissection, so that the discovery itself became the new level of understanding. What we witnessed seemed much closer to a change of paradigm which Kuhn has proposed is indicative of a fundamental alteration in the course of scientific understanding.⁴

I took a good clear piece of cork, and with a pen-knife, sharpened as keen as a razor, I cut a piece off Examining it very diligently with a Microscope ... I could exceedingly plainly perceive it to be all perforated and porous, much like a honey comb ... (I) found that there were usually about three score of these small cells placed end-ways in the eighteenth part of an inch in length ... more than a thousand in the length of an inch and therefore in a square inch above a million or 1166400, and in a cubick inch, about twelve millions, or 1259712000, a thing almost incredible, did not our Microscope assure us of it by ocular demonstration.⁵

The result of this technological invention coupled with the new science was a direct challenge to the old metaphorical way of understanding. What was seen now had an immediacy about it that could no longer be expressed rhetorically.

Instrumental reason now held sway. Nature was not merely to be lived with but could also be dominated by those who were

able to unlock its secrets with the new methods and tools of science.⁶ Reiser sees this discovery of the anatomist as providing the opportunity for doing medicine in a very different fashion because it resulted in a new view of illness,

that segregated disease and disorder to specific places in the body. This concept replaced the ancient Greek notion of illness as a dynamic process involving place and lifestyle and affecting the whole person. It has become the prevailing concept of the nature of illness and has influenced greatly the development and adoption of health care technology.⁷

Is it possible to argue, as does Reiser, that anatomists were responsible for developing a whole new perspective of disease which could be understood as a disorder of the body structure localized to a particular site, could now ask the question, "where is the disease?"⁸

The view which he sees emerging appeared fundamentally different from the prevailing humoral-physiologic one which had fueled medical understanding. This notion held illness to be a disruption of the balance between the basic constituents of the body and with the total environment; and was viewed as a condition affecting the whole person.⁹ With the rise of what Reiser calls the anatomical perspective, illness came to be seen as something affecting one aspect of the body.¹⁰

In his treatment of the same historical period, Eric Cassell fails to discover the dramatic break-through depicted by Reiser. Instead he finds it illustrative of the long-standing controversy between those who see disease as a

generalized event and others who hold it to be localized.¹¹ The first point of view, sometimes known as the physiological conception of disease was attached to the school of Hippocrates and saw the origins of disease as an imbalance between the forces of nature within and outside of the sick person. The other view, frequently termed the ontological conception of disease, depicts it to be composed of entities or things that invade the body and become localized in specific places within it.¹² In the person and writing of Galen, the physiological conceptions of Hippocrates and Aristotle dominated western medicine until modern times even if they were successfully challenged in the ancient world by Paracelsus. It is important to be aware that the "physiology" of the ancients referred not to the internal processes, as in the modern use of the term, but is derived from the Greek word "physis", which denoted the natural forces acting both without and within the person.¹³ Moreover, according to Cassell, it was only with Sydenham in the late seventeenth century that the ontological method began to re-enter medicine and its practice with some effect.¹⁴ And it was not until the work of Virchow on the cellular basis of disease and the bacteriological discoveries of the nineteenth century that this theory became the comprehensive method for understanding disease. Following Coulter, Cassell argues that even though Francis Bacon envisaged science as perhaps making its greatest contribution to human progress through medicine, it was surprisingly late in its real effect upon it. And while the

great discoveries of the anatomists and physiologists were of importance for the understanding of the human body, they were not of direct significance for doctors,

until the manifestations of sickness were systematized in a manner that allowed physicians to know when they were dealing with the same problem -- does this patient with rash and fever have the same disease as that patient with rash and fever?¹⁵

What was missing was a theory of medicine, one that could unify the actual phenomena exhibited by persons who were sick. The vitalist and mechanist theories had their ardent champions but held little relevance to what was happening to the sick patient and were of little use to clinicians. The basic effect of all this was to make the clinician a die-hard pragmatist who had little interest in theory and gave little value to its claims. What tended to be visible in western medicine was a major dispute between rationalist and empiricist, carried on independently from the theory of disease -- ontological or physiological -- which prevailed.¹⁶

The advent of the nineteenth century showed clearly the developments which produced the medical practices familiar to North Americans until very recently and which still remain enmeshed within the new high technology. Theoretically speaking, says Reiser, a logical justification toward specialization of health care was fueled by the anatomical perspective that tended to isolate illness to specific parts of the body. A practical justification for specialization was created by the need to develop and master a technology which would detect and treat these anatomical disruptions.¹⁷

In the 1830's, Lister introduced sterile operating procedures and this discovery was justified some fifty years later in the work of Robert Koch and others in the bacterial origins of disease. Hard on the heels of this basic science of bacteriology was the development of sophisticated instrumentation which allowed for the visual and chemical analysis of body fluids and tissues. Microscopes, incubators, staining agents, colorimeters formed the tools of the newly created diagnostic laboratory, and in turn produced a new group of technicians to make best use of these devices.¹⁸ This is Reiser's summary of the resulting effects upon the practice of medicine:

Physicians, impressed with the connection of these instruments and techniques to science, and thinking of themselves as practicing scientifically by using them, increasingly turned from the judgment of their own senses and the techniques of physical diagnosis to the impressive data of the laboratory This change was in keeping with the original emphasis of the scientific revolution of the seventeenth century. One of its tenets was to place inquiry on an objective basis. In the investigation of nature, it sought to eliminate evidence influenced by human values or bias. It attempted to establish a rigorous set of methodologies to establish facts, such as experimentation, and to describe the facts wherever possible in objective ways, such as through the use of numbers.¹⁹

Physicians seemed to believe that this new rigor, enveloped in objectivity, would finally allow them to take their place among those who were called scientists.²⁰ They had indeed come a long way toward this identification; since, by the early years of the twentieth century, diagnosis had forged a firm link with technology and surgery had ended its long

isolation from the rest of medical practice indeed giving notice that it might be in the vanguard of previously unattainable therapeutic activity.²¹ The consolidation of these movements is the history of medicine in the twentieth century, but it is our contention that in this process a second technological revolution has also taken place. Therefore, the three problems claimed by Reiser to characterize health care in this century:

first, how to organize rationally this growing technologic armory; second, how to distribute its goods among the increasing number of patients which it would benefit; and third, how to construct a fruitful relationship among patients, practitioners, and medical technology,²²

may not be altogether helpful for disclosing the shape of medicine in our time. It could be that what has driven the transformation of medicine has not, in fact, been the theoretical impulse provided by the anatomist but the pragmatic mind of the clinician and particularly the surgeon, the chief hand-maid of both being the equally practical interest of technology. Thus, it may be even more revealing to discuss the emerging problems of the twentieth century under the heading of theoretical problems inherent in the marriage of medicine, science and technology; structural problems presented by its various organizational forms; and relational difficulties developing from the complex social/political make-up found in sophisticated industrial society. What we will try to show is, that although the results of the changes in medicine may be understood partially as the issues upon which

Reiser focuses, their latter-day appearance has outgrown their bed in medicine considered in the developmental context he proposes and must be sought in a more complex understanding of the forces historically at work both inside and outside of medicine.

To turn to the question of theoretical matters²³ -- it will suffice here to show that there has been a noticeable lack of attention among doctors as to these issues considered either as philosophy of medicine, philosophy and history of science or parallel developments in areas of philosophy, religion and social theory which try to give form to theories of human nature, as well as the origins of society with its goals and structures.

... whether doctors like the idea or not, human action is inevitably theory driven. We act as we do (we even see what we see) because we have an idea -- a theory about what the consequences of our action will be.²⁴

It may well be the pragmatic bias of doctors that has prevented them generally from acknowledging that medical actions do presuppose some form of belief about cause and effect. At this level, physicians as a group have remarkably little in common because, either as individuals they hold theories which are at wide variance with each other; or those theories which are held in common are widely distanced from day to day clinical experience.²⁵ This caveat reveals itself in several different forms:

1. The current theory of medicine being in such disarray; the profession itself lacks coherence. The increasing

popularity of chiropractic reveals further the division between theory and pragmatism. Most patients do not go to these practitioners because they believe that the theory behind it is sound. Lured by modern medicine's obvious effectiveness and its tendency to stress success, the patient simply holds that this is the value which is transferable at will. The point of judgment is efficacy and the difference between chiropractic and scientific medicine is of little importance.

2. An examination of some of the basic ideas of classical science which are used by medicine, the social sciences and most citizens suggests they are badly out of step with the changing ideas of mid-twentieth century science. It is well known that the concepts of physics have revolutionized our views of space, time, and the relationships of objects to each other and to the observer.

One would not know this from medicine! The technological fruits of this theoretical upheaval are to be found throughout medical practice and research, but technology is not the subject.²⁶

There is also medicine's preoccupation with a form of factuality which is borrowed too simply from this outmoded view of science. This classical outlook employs an artificial construct of space, cancels out real time and does not consider the observer a part of the natural system being examined. While the derivation of these ideas from the earlier foundations of scientific theory is obvious enough and even explains how these concepts may be applied to

diseases considered as "things," it does not provide justification for their continued use.

... such notions are at wide variance with a system of medicine based on an understanding of pathophysiology. There, what is considered is the change of the organism through time -- process. And pathophysiology, in the modern understanding of it, extends beyond the boundary of organ system to include patient-initiated and environmental influences on the process. In such views of pathologic processes, space, time, and the observer become parts of the system.²⁷

3. An even greater problem has been located in the relationship of basic science to high technology. Another way of understanding the issues raised is provided by extending the discussion about theory. On the one hand, there is an identifiable trend in both medicine and science towards extending the complex systems approach to understanding and viewing the world of nature and of humans as one of constant change, as process rather than as a field of objects and events in static space. On the other, technology requires for its application a certain simplicity that contradicts the complex issues which its introduction raises. The more sophisticated high technologies defy insight which previously governed our understanding of these tools as extensions of the person.

... modern technologies demand an unambiguous and non-metaphorical compliance with their rules of use. Alas, ambiguity and metaphor are what distinguish us from the inanimate and allow us to live together. Thus, as the human spirit seems to strive towards a richer view of nature, our love of technology turns us constantly back toward the simple. This is not necessarily so, but merely a matter of time required for a sophisticated people to accommodate to these newer tools.²⁸

4. There are also definitional questions which cover matters pertaining to the nature of health,²⁹ disease and illness;

professional problems which reveal the complexity of specialties and fields contributing to health care as well as the social role assigned to groups of persons with specialized knowledge which includes special legal and moral status.³⁰

Some mention should be made of the simultaneous developments in philosophy, religion and social theory which give additional substance to the argument just presented. The clever distinctions of Descartes' dualism enabled science to go ahead with its agenda by occupying the Church with non-material matters. The slice given to science was the world of the measureable and this became the working definition of the Western view of the world until very recently.³¹ The novelty of more recent movements has been to place a very different perspective on the intellectual history of modern thought. Critical theory, the science of hermeneutics, the reformulation of concepts of culture now suggest that the approach to data which typified the heirs of Descartes, including positivism is exceedingly stunted and leaves no room for other developments of human creativity upon which science itself is heavily dependent.³²

This brief summary suggests another direction for further exploration, namely, the extent to which these theoretical issues have been subsumed in attempts to treat them as structural and/or relationship matters with methodological or bureaucratic solutions.

We begin with some comments about the structural responses. It is interesting to note how frequently North

American approaches to major questions apply the metaphors associated with war. The U.S. Public Health Service is paramilitary in its structure complete with uniformed personnel and is headed by a surgeon general. The hospital became a means for organizing specialized personnel, technology and patients to treat illness in ways which have a surprising similarity to the command structure of the military.³³

As an organization it showed a penchant for specialization which was given the opprobrium of necessity as early as 1912 by William Mayo:

So vast is the extent of knowledge to be gained of disease that no one man can hope to accomplish more than a small share during his lifetime. The old-time family practitioner has passed away and with him has passed individualism in medicine.³⁴

- However, by 1930 individualism among physicians had wilted only to the extent that 1 in 4 was a specialist and significantly in view of our contention that a second high technology revolution in medicine has occurred it was not until 1980 when 4 out of 5 doctors were now engaged in specialty practice. Nonetheless, the real issue by then may not be specialty practice alone. The heart of the matter may be what such fragmentation means, not just structurally and in relationship to patients; but theoretically, as it applies to theory of disease and determines notions of health and illness. An illustration of the confusion may be found in the attempts to provide institutional solutions, viz.

patients' representatives or even ethics committees in order to deal with problems arising from considering the patient as

a whole.

It seems reasonable to conceive, however, that for much of the twentieth century the problem of fighting disease as seen by physicians was best conceived of in terms of having an appropriate organization.

At the start of the twentieth century, for example, there were about 345,000 health care providers, of whom about one in three were (sic) physicians. Most of the other were nurses. But gradually, as the century progressed, the demand for the expeditious performance of specialized tasks introduced into health care a new cadre of people to run the burgeoning technology and to perform new tasks generated by the acquisition of knowledge. In the mid 1960's, this heterogeneous group of individuals became called allied health personnel; by the mid-1970's their number in the United States had reached some 1.8 million. Included within their ranks were 152 different specialists -- such as cytotechnologist, health physics technician, dietitian, and rehabilitation therapist. The health care force at this time numbered 5.1 million people, of whom only 1 in 13 was a physician (National Commission on Allied Health Education 1982). If one now adds the 152 allied health specialists to the 23 major specialties among physicians and 8 among dentists, and then takes account of the specialties of nursing, optometry and other health professions, one finds that there exists today over 200 specializations (Wilson and Neuhauser, 1980), whose practitioners must somehow focus on the object of the whole enterprise -- the patient.³⁵

Viewed from this perspective, it is easy to see why the best response or at least the one devised by the twentieth century in the western world has been the hospital. The rationale given is quite simple. What other way would there be to organize personnel and machines so that the needs of an individual patient can be met not only efficiently but humanely? It is then possible to devise a list of the requirements for efficient hospital function. One illustration will suffice to show the kind of development we have in

mind. Among the most important are the means of linking the separate medical interventions of diverse people. This has led to the creation of the medical record.³⁶ The manner in which record keeping has evolved also encouraged hospital dependence as the most efficient means of providing medical care because it was bulky, hand written, difficult both to store and to transmit and all too frequently almost impossible to find even within the institution in which it was generated.³⁷ It is true also that it is not really possible to function medically at the level of any sophisticated technology without it. At the same moment that high technology is introduced into record-keeping through the computer, it makes demands which alter the practice it is intended to assist. This is noticeable particularly in the way that non-quantifiable data is handled by a tendency to reduce the "life" of the patient to the test values recorded.

Further analysis of the part played by technology in creating the central role for the hospital in current medical practice indicates that as an organizational response to specialization this institution has shifted from a military model to one strikingly similar to that found in industry.³⁸ The resulting difficulties, particularly at the human level, may illustrate the reluctance of medicine to engage in sufficient theoretical reflection and its failure to comprehend the social/political form in which relational issues surface in complex western industrial society. It may be due also to the organizational naivete found until quite recently

in medical practice organization.³⁹ As Reiser and others have pointed out, prior to the medical care revolution attributed to the twentieth century, health care was a highly decentralized undertaking. While many of the reasons for this condition may be attributed to the futility of pooling the states of ignorance and helplessness that doctors faced in their struggle with disease, there was an appreciation of the positive aspects of the old style of medical practice. Even now it served sometimes as the model of the physician/patient relationship⁴⁰; however, that relationship has become the sum total of a series of fleeting personal meetings. Does it add up to the same thing, that is, an identifiable event of personal dimension? The question produces many different responses.⁴¹ The most important issue may be whether or not the personal encounter in medicine was merely an appropriate response to the physician's ignorance which underlay it and is now an unfortunate anachronism in contemporary high technology medicine which has a very different parameter of expectations because it is dominated by the expectation of the successful outcome. The other point which needs to be made is that the venue of health care was not an item of specific interest prior to the present century. To note this means that the very meaning of the term decentralized has changed as the result of the new developments in medical practice.

The current scene in medical practice then does not just present three problems as Reiser suggests, although, of

course, these questions are still around. They are in fact not answerable as they stand and it is to the quest of their reformulation that we turn now, in an attempt to develop from our analysis of theory, structure and relation a sense of what has taken place.

1. However powerful individually or collectively the physician may be, the role in the practice of health care has been drastically altered.⁴²

2. The technology which is coming into place today was not anticipated and will alter the delivery of health care now at least as dramatically as the first technical wave did.⁴³

3. The facilitation of communication is a major issue both within the hospital as well as within the health care system. The focus of the problem is the medical record, and while an electronic system is obviously a tremendous improvement on the traditional system, it is only a partial response to a much larger theoretical and structural impasse. The best way of formulating the precise nature of what we're left with is not clear,⁴⁴ however:

4. It is related to the previously unimportant condition of the venue or locale in which services are delivered in the sense that almost all delivery of service has been institutionalized in some form.⁴⁵

5. Not just knowledge, but increasingly treatment, is becoming highly specialized and replacing communication (the medical record) as the organizing principle of hospital care.⁴⁶

6. The grouping of patients according to disease and treatment potential produces tremendous pressures upon the method used to determine the allocation of resources within a health care system particularly in the face of the fact that high technology and increasing costs are inseparable in medical care.⁴⁷

7. In view of the above to speak about centralization or decentralization of health care delivery makes no sense. The concept becomes a matter of efficiency only after the matters of allocation, viz. the justice and fairness of the system have been decided.⁴⁸

8. The growth potential of a system employing high technology is essentially limitless and the problem of control must be based upon the realization that medical science is capable of creating more therapeutic agents than it and society have the capacity to give to those who might benefit from them.⁴⁹

9. There is only in rare instances a single specific entity capable of being called the medical relationship⁵⁰ (in spite of the existence of so-called primary care physicians); rather an immense variety of relationships which are possible between the patient and the doctor or other health care personnel. Viewed in its totality it has to be said of the health care system that the needs of the patient as person fluctuate widely and may be considered to be less important than the realization of justice and fairness through allocation of resources. This is undoubtedly a highly disputable contention. It may be justifiable on the following

grounds: it is not intended to counter the notion that fundamental humanness involves far more than the idea of the body as the focus of disease; it acknowledges the limitations of high technology are far greater than its successes in curing disease and will remain so for the foreseeable future; it is intended to highlight the fact that high technology has redefined medical need as that which is susceptible to its ministrations and therefore what is required is a more precise way of confronting the implications of this change.

10. Similar problems confront the countries in the western industrialized world not just in the area of health care but in other areas of social concern.⁵¹

The intention of this historical-analytical survey of modern medicine has been to show the nature of the changes which have been produced in what has come to be called clinical practice. The term clinical itself while pointing to the source of medical care, in the ancient Greek world has come to symbolize the evolving methodology of medicine in the nineteenth and twentieth centuries. It was given much of its present form by Bernard and Osler who provided it its foundation in the basic sciences and clinically oriented teaching and research. The contribution of technology to this transformation has been duly noted. At the same time it has been argued that the current set of issues and problems found in medical practice suggest that they are something more than a different version of those previously identified. In North America particularly, the tendency has been to fix upon

dollar cost as the basis for determining the culprit responsible for this current crisis in the health care.⁵² In rejecting this finding as substituting a symptom for the real cause we wish to argue that the effects of a style of practice depending upon the use of high technology deserves more consideration. One of the signs of this change has been located in the increased use of efficacy and efficiency measures to validate medical practices and procedures. Another is the necessity to consider the practice of medicine as subsumed into something which is called a health care system. We have also noted the increasing organizational similarity between the practice of medicine and other large scale industries.

We seem to be left with a need to develop a series of questions which will highlight the setting of the practice of medicine today. This interrogation will serve also to uncover the values which are expressed in the way in which we care for persons medically. How will the amount of calculation such as risk and benefit which has entered the vocabulary of health care today be related to more traditional ways of valuing which are found in our philosophical and religious traditions? How can the human dimensions enter into calculations of this sort? Will this emphasis upon positive results end up denying care to those who are so unfortunate as to end up untouchable by technology? Perhaps we are ready to consider what high technology is for the practice of medicine.

... high technology (HT). But when is a technology so regarded? This must be arbitrary because some of today's HT may become tomorrow's low technology, as

some of today's research becomes tomorrow's routine. For my purpose I propose an operational definition of HT -- that it is complex and expensive, with the consequence that it is restricted in availability -- usually to a limited number of places where it is under the control of a specialist staff. It follows from this that demand for its use exceed supply so that some form of explicit rationing is required. It is possible to analyze HTM according to the type of machine or instrument used -- radiological, endoscopic, anaesthetic, and so on. But the debate about HTM is less about the secondary influence that increasing use of HTM may have on the practice of medicine That requires consideration of where HTM fits into the agenda of the medical task.⁵³

Footnotes to Chapter II

¹Robert G. Evans, Strained Mercy, The Economics of Canadian Health Care (Toronto: Butterworths, 1984), pp. 267-268.

²Stanley J. Reiser, The Machine at the Bedside, p. 5.

³Ibid., p. 5.

⁴Thomas Kuhn, The Structure of Scientific Revolutions (Chicago: University of Chicago Press, 1962).

⁵Robert Hooke, in S. J. Reiser, The Machine at the Bedside, p. 5.

⁶Ibid., p. 5.

⁷Ibid., p. 5.

⁸Ibid., p. 6.

⁹Ibid., p. 5.

¹⁰Ibid., p. 6.

¹¹Eric Cassell, "Ideas in Conflict: The Rise and Fall (and Rise and Fall) of New Views of Disease," p. 19; C.f. Robert P. Hudson, Disease and Its Control: The Shaping of Modern Thought (Westport, CT.: Greenwood Press, 1983), Chapters 4 and 6.

¹²Eric Cassell, "Ideas in Conflict" p. 19; C.f. F. Kraupl Taylor, Concepts of Illness, Disease, and Morbus (Cambridge, England: Cambridge University Press, 1979), Chapter 2.

¹³Eric Cassell, "Ideas in Conflict", p. 19; c.f. Harris L. Coulter, Divided Legacy: A History of the Schism in Medical Thought, Vol. I (Washington, D. C.: Wewawken Books, 1975), pp. 307ff.

¹⁴D. G. Bates, "Thomas Sydenham and the Medical Meaning of Method," Bulletin of the History of Medicine, Vol. 51, 1977.

- ¹⁵Eric Cassell, "Ideas in Conflict," p. 20.
- ¹⁶Harris L. Coulter, Divided Legacy: A History of the Schism in Medical Thought, Introduction.
- ¹⁷S. J. Reiser, The Machine at the Bedside, p. 7.
- ¹⁸Ibid., p. 8.
- ¹⁹Ibid., p. 8.
- ²⁰Ibid., p. 8.
- ²¹Ibid., p. 8.
- ²²Ibid., p. 8.
- ²³Thomas McCarthy, The Critical Theory of Jurgen Habermas (Cambridge, Massachusetts: MIT Press, 1978), p. 137ff.
- ²⁴Eric Cassell, "Ideas in Conflict," p. 21; c.f. Popper and Eccles, The Self and Its Brain (New York: Springer International, 1977).
- ²⁵Ibid., p. 21; Edmund Pellegrino and David Thomasma, A Philosophical Basis of Medical Practice (New York: Oxford University Press, 1981).
- ²⁶Eric Cassell, "Ideas in Conflict," p. 32.
- ²⁷Ibid., p. 33.
- ²⁸Ibid., p. 41.
- ²⁹Arthur Caplan, The Concepts of Health and Disease, n.d., unpublished paper; H. Fabrega, "Concepts of Disease: Logical Features and Social Implications," Perspectives in Biology and Medicine, Vol. 15, 1972, pp. 538-617; E. Pellegrino and D. Thomasma, A Philosophical Basis of Medical Practice, pp. 74ff.
- ³⁰Paul Starr, The Social Transformation of American Medicine (New York: Basic Books, 1982), p. 18, 220f.
- ³¹Eric Cassell, "Ideas in Conflict," p. 32.

³²Cf. M. Polanyi, Personal Knowledge -- Towards a Post Critical Philosophy (New York: Harper and Row, 1958).

³³P. Starr, The Social Transformation of American Medicine, p. 169; there is an interesting penchant for military metaphors as well. Death is the great enemy; there is a constant war against disease.

³⁴S. J. Reiser, The Machine at the Bedside, p. 9.

³⁵Ibid., p. 9.

³⁶Ibid., p. 10.

³⁷20% c.f. S. Fletcher, "Medical Care in Teaching Hospital: How Good Is It?" McGill Medical Journal, Vol. 44, Fall/Winter 1975, p. 8.

³⁸P. Starr, The Transformation of American Medicine, pp. 154ff, 428ff.

³⁹Ibid., pp. 143-144.

⁴⁰Jay Katz, The Silent World of Doctor and Patient, 1984; Eric Cassell, "The Changing Concept of the Physician," pp. 185-208.

⁴¹S. J. Reiser, The Machine at the Bedside, pp. 16ff.

⁴²Ibid., p. 9; Eric Cassell, "The Changing Concept of the Ideal Physician," pp. 185ff; E. M. Gruenberg, "The Failure of Success," Milbank Memorial Fund Quarterly/Health and Society, Winter 1977, pp. 3-24.

⁴³S. J. Reiser, The Machine at the Bedside, p. 16.

⁴⁴Ibid., p. 11.

⁴⁵Paul Starr, The Social Transformation of American Medicine, pp. 428ff.

⁴⁶Ibid., pp. 355f.

47 J. K. Inglehart, "The Cost and Regulation of Medical Technology: Future Policy Directions," Milbank Memorial Fund Quarterly/Health and Society, Winter 1977, pp. 27-28.

48 M. Drummond, "Cost Effective Analysis in Health Care," Nuffield/York Portfolios, Folio 6, Abingdon, U.K., Nuffield Provincial Hospitals Trust; G. Mooney, "Valuing Human Life in Health Policy Service," Nuffield/York Portfolios, Folio 3, Abingdon, U.K., Nuffield Provincial Hospitals Trust; A. McGuire, "Ethics and Resource Allocation: An Economist's View," Social Science and Medicine, Vol. 22, No. 11, 1986, pp. 1167-1174.

49 S. J. Reiser, The Machine at the Bedside, p. 15.

50 Ibid., p. 16; Eric Cassell, "The Changing Concept of the Ideal Physician," p. 186.

51 E.g. ecology and such matters as air and water pollution, use of non-renewable resources, destruction of rain forests, etc.

52 J. Ingelhart, "The Cost and Regulation of Medical Technology: Future Policy Directions," pp. 25-28; J. A. Showstack, et al., "The Role of Changing Clinical Practices in the Rising Costs of Hospital Care," New England Journal of Medicine, Vol. 313, No. 19, November 7, 1985, pp. 1201-1207; R. R. Bovbjerg, et al., "Provider-Patient Relations and Treatment Choice in the Era of Fiscal Incentives: The Cost of the End-Stage Renal Disease Program," The Milbank Quarterly, Vol. 65, No. 2, 1987, pp. 177-202; A. Caplan, "So How Are We Doing?" -- Press Coverage of Recent Developments in Health Care Presented at ASNE Annual Meeting, April 10, 1985.

53 Bryan Jennett, High Technology Medicine, pp. 4-5.

CHAPTER III

MAKING TIME?

Bryan Jennett has developed a comprehensive description of the effects of high technology (HT) upon contemporary medical practice. Like Reiser and others, he sees that there is a strong sense in which HT is an extension of previous uses of technology because,

(m)ost of the tools of medical technology can be regarded as fulfilling one of five technological tasks. They are visualization of parts of the body, measuring physiological function, substituting lost function, contributing to surgical procedures, and the processing of information.¹

This functional analysis of technology is not particularly revealing for someone searching for the changes produced by high technology and is really more indicative of the fact that technological tools have fit very well into traditional procedures. However, it is obvious also, that increasing numbers of medical activities contain such a "proportion of HT that they are immediately recognizable as HT packages -- e.g. intensive care, renal dialysis and transplantation, and open heart surgery."² Obviously this does not exhaust the list of packages currently available nor does it begin to suggest that nature of the process by which these treatment innovations become features of the health care system armamentarium.

Elsewhere³ we have noted and developed Jennett's contention that HT has led to placing the medical task in an ordered agenda of Diagnosis, Prognosis, Decisions and Management; and, has introduced another category of activity which he has called rescue that fills the gap between caring and curing. Rescue involves entering some very muddy waters since it tends to be applied in,

life threatening situations -- though the threat need not be immediate nor the intervention an emergency. Rescue procedures are often successful in postponing death and they sometimes result in cure. More often they extend the period of survival of disabled patients; sometimes their quality of life is much worse after rescue than it was before the crisis that called for rescue. Consequently doubts can arise, even in the minds of caring relatives, as to whether the rescue has been worthwhile -- even though in strict medical terms it may have been judged to have been "successful." Rescue procedures include intensive care, renal dialysis and transplantation, much open heart surgery and neonatal surgery and a good deal of oncology. Rescue usually involves HT and it is not surprising that they share many characteristics -- limited availability of specialized equipment and staff and high cost.⁴

At the same time this HT equipment is available for and used for cure or palliation, and so warrants an important distinction between HT per se and how it is used.⁵ We wish to focus upon the possibilities opened up by HT in its application to rescue as being particularly significant. They are an issue in the practice of calculable life extension. They force the system to examine the inherent meanings of cost in ways previously unnecessary and unnoticed.

The last concern voiced by most in the health care technology field is directed to the social impacts of technology. Over time the issues raised by health care technology, particularly halfway

technologies, have become no less complex than they were when it was first recognized that lives could be saved with potentially minimal benefit to the patient. As noted in the introduction to this chapter, organ transplantation has, once again, forced us to confront these issues. The issues include questions such as the following: Who shall receive an organ transplant? How shall we decide? What are the long-term consequences of organ transplants? How should we decide? Who will pay? What is the proper role of the (US) federal government? How do we treat the medically indigent? These questions are both complex and nearly metaphysical.⁶

A somewhat similar observation has been made by Banta:

(1) ethics and morals, changing or challenging our fundamental values or beliefs; (2) the legal and political system, pertaining to allocating scarce resources, defining life and death, informed consent, and so on; and (3) the economic system, going beyond issues of the cost of health care by affecting such factors as employment, productivity, and the necessity for and size of income maintenance programs.⁷

Evans summarizes these effects with the words:

Clearly, while the development of medical technology is in the best interests of all, including the healthy, the implications of medical technology can often go beyond the mere practice of medicine. Ultimately, decisions must be made as to how society will allocate the available resources. Such decisions are necessarily somewhat removed from the practice of medicine per se.⁸

The impact of this change is more easily shown through historical analysis. For as long as records exist medical care has been understood as a highly individual affair which has found expression through the concept of the doctor/patient relationship. In western thought this approach has found resonance with ancient and modern philosophical and religious expression. The following are typical examples: the

Christian understanding that each person has a specific individuality conferred by the presence of his soul; the Kantian categorical imperative. What all of this tradition has in common is that it applies to the diagnosis and treatment of disease on the basis of very limited knowledge.

There is a sense in which it is not unfair to argue that what knowledge there was tended to be more religious and philosophical in character -- physicians were individuals who learned by practice how to apply this knowledge to the problems generated by disease. The strength of this tradition was its wisdom about the nature and character of the human person and the potential of his reason. The weakness of this knowledge bank was its inability to comprehend the natural setting of which the human person and his reason were an expression.

There is some agreement among those who have studied the development of medical practice in the twentieth century that somehow in the 1960's a consensus developed about the superiority of the hospital practice of medicine to such an extent that it became the major source of health care costs.⁹ The elements which produced this transformation included:

1. the knowledge produced by new inventions as well as the cumulative effect of more established ones;
2. discoveries in basic science which dramatically altered the knowledge base of medicine;
3. the potential of both for suggesting new forms of organizing and sharing the knowledge and technology now

available;

4. the geometric increase of government funding which was a fall-out from unprecedented economic growth in the United States and Canada;
5. the realization that a systems analysis of problems had a far wider potential than those immediately applicable to the engineering matrix where it was developed;
6. a more industrial approach to health care issuing from the increasing presence of third parties who would pay all or part of patient's medical expenses;
7. a growing conviction that health problems and disease were susceptible to an unheard of level of amelioration because essentially unlimited amounts of money were available for research and treatment;
8. the succumbing of this fledgling system to the effects of the techniques of marketing because not only was there the possibility for doing unprecedented good there was the lure of enormous profit to anyone who could create or supply the technology, including drugs.¹⁰

A very good illustration of how dramatic was the change produced can be seen in the paucity of moral or ethical thought which covered what was going on. The strengths and limits of wisdom on the subject was pretty well confined to Pius XII's speech on the use of ordinary and extraordinary measures to preserve life which does not foresee this distinction being outflanked by the constant development of new technologies, today's extraordinary, tomorrow's

ordinary.¹¹

The word that keeps returning in the struggle to understand what all this means is COST. Within the sense of this idea are not only the concepts of efficacy and efficiency as well as the dilemmas of allocation, but also the matters relating to value and valuing which are fundamental to our moral and ethical systems. As a result, the use of the term cost becomes much less a matter of reducing health care problems to a matter of containing financial outlays to a predetermined level and much more the question of value calculation. In real life, this difference may be portrayed by those who give strong support to the concept of reducing the total health care bill yet at the same time worked very hard to see that the (US) National Center for Health Care Technology was killed because as Jennett observes: "Its promise of success so threatened certain vested interests that it became a target for abolition and Congress yielded to these lobbies."¹²

Another observer¹³ has noted that these opponents included professional interests which claimed that systematic assessment would stifle innovation. To learn much about the identity of HT, we might explore the various avenues of "costing," whose creation it has stimulated, and at the same time, try to answer the question as to why this kind of evaluation is now so crucial.

The particular form in which this material is presented has been organized to play upon the ethical nuances

which are offered by the concept of cost. It is our contention that employing these technical categories in this manner will not distort the function which they have in their more usual location in economics, social science and scientific assessment.¹⁴ The most basic concepts are those of efficacy and effectiveness.¹⁵ The former refers to whether a practice, drug or tool will work at all; and the latter, the circumstances in real-life in which it is employable. On face value it would seem that determining if something works should be a relatively simple matter but in practice this is far from the case. The previous discussion of the practice of clinical experimentation and investigation has shown that extensions of knowledge discovered on the animal model rarely encounter a perfect fit.¹⁶ The history of heart transplantation has shown that the discoveries which led to efficacy and efficiency were nearly simultaneous processes and we suspect that this experience is repeated more often than not when it comes to the emergence of a HT procedure in medicine.¹⁷ The difficulty of separating these two elements is what sets up the need for technology assessment. Put another way, it would seem that one of the characteristics of HT is that it must proceed quite far along the path of development before an informed judgment can be made of its value or even if it will work. This leads to the further complication that often these projects are advocated by particular groups which may expect to benefit from them and it is far from clear that the wider interests of society coincide with those of the project advocates.¹⁸

Another difficulty attached to this very basic assessment structure is the confusion in many quarters between the goals and methods of basic science research and those employed in the development of HT devices and procedures. The training of persons employed in both of these efforts may be essentially the same, but seen from the point of view of essential social need each represents a fundamentally different value in the structure of human society. The distinction which best represents this difference is based upon the concept of knowledge they stand for. The prepositions "of" and "for" are useful markers for determining the relationship in which each stands to human society. The one, science, is ontological; the other, technology, is utilitarian. This is the reason why cost is a necessary element in determining what role technology should play in the practice of medicine. It is also important to remind ourselves of why this approach to evaluation is so controversial for medical practice. The doctor/patient relationship which is the basis for western medicine is thought to be exempt from this form of calculation. It is interesting to speculate as to why the humanistic structure of the doctor/patient relationship was not fundamentally threatened by the shift of medicine to the scientific mode, but has been tattered by the introduction of high technology and the consequent alteration of the institution of the hospital.¹⁹

In arguing that the role of science in medicine must be distinguished from the role of high technology, we have tried

to prepare a case that suggests there is an elective quality in the employment of technology in medical practice which does not hold for that of science. In practice, the separation may be difficult to make.²⁰ With this potential caveat in mind, we will now continue to develop this presentation of the techniques of costing in order to see if they may produce better definition of the elective nature of technological innovation. Cost effectiveness, cost utility and cost benefit²¹ are highly dependent upon the existence of some measure of efficacy and efficiency. In the absence of reliable figures for relating workability (efficacy), resort is often made to the statistical methodology of sensitivity analysis.²² In this practice the doubtful parameter or parameters of outcome are assigned a range of values deemed plausible by the investigator and/or expert advisors and a calculation is made which offers some indication as to how these best guesses fit to plausible ranges of acceptability. The manner in which what works is established and the tools employed may be clinical and/or epidemiological but it is important to note that what results is a "can" and not necessarily a "should."²³ The decision to proceed must come from some other sources within the system. These other considerations which produce the go ahead may be either explicit or concealed. For the moment we will be content to pursue further concepts of "costing" which may be explicitly brought to bear on the decision-making process.

There is the way of cost effectiveness which is a measure

of outcome in terms of numbers of some natural unit such as lives saved or accidents averted calculated as cost per natural unit. The cost of this unit is compared to the value assigned to this same unit. The valuing process may be viewed from a number of perspectives or a combination thereof, viz. political, social, moral, religious, etc. An examination of these points of view reveals some interesting dilemmas: A religious tradition may see each unit (child, person) as having infinite value; a social outlook may prefer potential for contributing to a social goal such as ability to reproduce; a political perspective may try to reconcile the conflict by distinguishing between views which reflect personal preference and those which are subject to general goals which are reserved for the state. Several attempts have been made to determine the cost effectiveness of both kidney and heart transplantation.²⁴ In the case of kidneys the comparative procedure is long term dialysis. Several studies indicate that the current survival figures for cadaver kidneys make transplantation the more cost effective treatment for persons in end-stage kidney failure.²⁵ Results for heart transplantation are somewhat more difficult to subject to this form of analysis. One group used coronary by-pass surgery as the comparison and found that, projected over a longer period of time, a good case could be made for the effectiveness of transplantation.²⁶ One of the principal limitations to investigations of this type is the absence of such studies over a wide enough range of treatments and

procedures to enable us to know how significant this measure is as a rationale for allocating resources.

An improvement on this method, which is said to overcome this absence of shared value, is provided by the concept of cost-utility which converts the units of output to a common measure -- their relative value to those experiencing a particular outcome. Life Years is a current form of this method.²⁷ These have had some application to heart transplantation evaluation particularly in quality of life studies,²⁸ but in addition to the more general criticism noted below they seem to have limited ability to predict how a person will act when actually confronted with the situation in vivo. From the broader perspective it is important to stress what this so-called common measure can and cannot contribute to the decision-making process. The distinction which needs to be made is between personal preferences which are generalized to apply to groups of persons who are presumed to be in the same category (viz. all persons suffering from end-stage heart disease) and values which are held in common because they are expressive of those principles which make a social fabric possible. Cost utility is a way of determining what a defined group of individuals may feel about possible outcomes as applied to their case; it does little toward solving the question of relating this group of needs to overall social goals or benefits. There is the added problem of the nature of needs as they appear in the health care system. There is a growing dossier of evidence which

suggests that many health care needs particularly those associated with HT, are physician generated.²⁹

Possibly the most comprehensive of the costing concepts is that offered by cost-benefit analysis. It tries to identify all costs and consequences across the whole society and values each with a common unit which is generally monetary. From this point of view, an activity becomes worth doing if its present net value (dollar benefits less dollar costs, each appropriately discounted) is positive.³⁰ One of the ingredients of cost-benefit deserves special mention because it has been particularly associated with attempts at HT evaluation. This is the Quality of Life measure. The rationale for this assessment is noble; obviously it would be reprehensible to offer as treatment a procedure whose outcome left the patient little better off than before, or even in a state "worse than death." On this measure two separate teams have determined that heart transplantation is viewed as providing very good results.³¹ The whole approach is of limited usefulness because it is much better at providing "rule out" information than "rule in" and the real battle in resource allocation is over competing successes.

In summary we can say that so far the results produced by cost benefit studies have been marred by two problems both of which arise from the use of monetary means to weigh and resolve costs and consequences across the whole of social organization. The first has been the inability to estimate straight dollar costs of implementing a procedure entirely

apart from the attempt to promulgate its benefits. As we have noted elsewhere, we offer as examples the original estimates for the costs of funding kidney dialysis in the United States or the claims produced by committees studying the appropriateness of developing an artificial heart which have been wildly inaccurate. One possible cause for this inaccuracy should be mentioned and that is the domination of these studies by those who have a vested interest in the programs.³² The second problem is that attractive as the idea may be, cost benefit ends up claiming that complex addition is a substitute for the political, ethical, moral and religious processes which determine the goals of human society. Nonetheless, the failure of this attempt should not lead to its dismissal out of hand. Why?

1. Because the complexities introduced into the process of decision-making by complex systems such as health care demand that rational methodology has to be taken as far as possible;
2. the concept of costing is one way of trying to locate and weigh all the factors involved, but
3. requires a more sophisticated scheme of translating the meaning of Benefit into concepts which are commensurate with the value language used in politics, ethics and religion.

Apparently what is called for is a method for generating a dialogue between the various parties involved in calculating and weighing the values which enter into the

social/political institution that we call health care. It is the argument of this thesis that our religious tradition has a contribution to make toward this process. We need now to define this religious legacy.

Footnotes to Chapter III

¹Bryan Jennett, High Technology Medicine, p. 5.

²Ibid., p. 9.

³Chapter I, p. 24.

⁴Bryan Jennett, High Technology Medicine, pp. 4-5.

⁵Ibid., p. 5.

⁶R. W. Evans, "Health Care Technology and the Inevitability of Resource Allocation and Rationing Decisions," Part I, JAMA, Vol. 249, 1983, pp. 2047-2053; Part II, JAMA, Vol. 249, 1983, pp. 2208-2219; see also R. W. Evans, National Heart Transplantation Study, 41-12.

⁷H. D. Banta, et al., Towards Rational Technology in Medicine (New York: Springer, 1981), p. 19; R. W. Evans, National Heart Transplantation Study, 41-12.

⁸Cf. R. W. Evans, National Heart Transplantation Study, 41-12.

⁹This is not to imply that major transformations of medicine had not occurred previously. We noted earlier that science, technology and medicine had an increasingly fruitful partnership beginning in the mid-nineteenth century.

¹⁰Robert G. Evans, Strained Mercy, p. 226.

¹¹S. J. Reiser, The Machine at the Bedside, pp. 13-15.

¹²B. Jennett, High Technology Medicine, p. 142.

¹³D. Dutton, Dilemmas of Medical Progress -- Health Risks and Social Choice (working title) from the Department of Medicine, Division of Health Research and Policy, Stanford University, Draft and undated, Chapter 1, p. 3.

¹⁴A similar adaptation from the viewpoint of the economist has been made by Robert G. Evans, Strained Mercy, 1984, c.f. p. 265.

¹⁵Ibid., p. 371; A. Caplan, "How Should Values Count in Allocation of New Technologies in Health Care?", in R. Bayer and A. L. Caplan, In Search of Equity (New York: Plenum), pp. 95-124.

¹⁶R. Fox and J. Swazey, The Courage to Fail, pp. 67-70.

¹⁷R. W. Evans, The National Heart Transplantation Study, 42-1-7; D. L. Sackett, "Pitfalls and Biases in Evaluating New Therapeutic Technologies, in B. J. McNeil and E. G. Cravalho, Critical Issues in Medical Technology (Boston: Auburn House, 1982), pp. 81-89; G. E. Markle and D. E. Chubin, "Consensus Development in Biomedicine: The Liver Transplant Controversy," The Milbank Quarterly, Vol. 65, No. 1, 1987, pp. 1-24.

¹⁸D. Dutton, Dilemmas of Medical Progress, Chapter 1; see also the debate on the development of the artificial heart -- Office of Technology Assessment, Congress of the United States, The Implications of Cost-Effectiveness Analysis of Medical Technology, -- Background Paper #2; Case Studies of Medical Technologies -- Case Study #9; The Artificial Heart: Cost, Risks and Benefits, 1981; Margery Shaw, After Barney Clark (Austin, Texas: University of Texas Press, 1984).

¹⁹It may be that ~~positivism~~ to the contrary, science and the practice of medicine share the same complex understanding of subjectivity and objectivity.

²⁰Cf. the work of Jacques Ellul.

²¹R. G. Evans, Strained Mercy, p. 370.

²²Ibid., pp. 266-268.

²³Ibid., pp. 265-267.

²⁴R. G. Evans, The National Heart Transplantation Study, Chapters 27-30; M. Buxton et al., Costs and Benefits of the Heart Transplant Programmes at Harefield and Papworth Hospitals, Chapters 4-7; M. A. Robinette and C. R. Stiller, "Background to the Task Force: Health Care and Financial Implication," in Organ Donors in the Eighties: The Minister's Task Force on Kidney Donations, Transplantation Proceedings, Vol. XVII, No. 6, Supplement 3, December 1985, pp. 5-7; R. D. Guttman, "Renal Transplantation," New England Journal of Medicine, Vol. 301, Nov. 1 and Nov. 8, 1979, pp. 975-982; 1038-1048.

²⁵M. A. Robinette and C. R. Stiller, "Background to the Task Force and Financial Implications, p. 7; P. Tousignant, R. D. Guttman, and D. J. Hollomby, "Transplantation and Home Dialysis: Their Cost-effectiveness," Journal of Chronic Diseases, Vol. 38, No. 7, 1985, pp. 589-601.

²⁶M. Buxton, Costs and Benefits of the Heart Transplant Programmes at Harefield and Papworth Hospitals, Chapters 12 and 13; R. W. Evans, "The Socioeconomics of Organ Transplantation," Transplantation Proceedings, Vol. XVII, No. 6, Supplement 4, December 1985, pp. 129-136.

²⁷R. G. Evans, Strained Mercy, p. 370, 259-261; J. Harris, "Qualifying the Value of Life," Journal of Medical Ethics, Vol. 13, 1987, pp. 117-123; J. M. Najman and S. Levine, "Evaluating the Impact of Medical Care and Technologies on the Quality of Life: A Review and Critique," Social Science and Medicine, Vol. 15, Fall 1981, pp. 107-115QC.

²⁸R. W. Evans, The National Heart Transplantation Study, Chapters 23-26; M. Buxton, Costs and Benefits of the Heart Transplant Programmes at Harefield and Papworth Hospitals, Chapters 9 and 10; M. E. Lough et al., "Life Satisfaction Following Heart Transplantation," Heart Transplantation, Vol. IV, No. 4, July-August 1985, pp. 446-449; M. J. McAleer et al., "Psychological Aspects of Heart Transplantation," Heart Transplantation, Vol. IV, No. 2, February 1985, pp. 232-233; Virginia O'Brien, "Psychological and Social Aspects of Heart Transplantation," Heart Transplantation, Vol. IV, No. 2, February 1985, pp. 229-231.

²⁹R. G. Evans, Strained Mercy, pp. 97, 22ff. See also T. Beauchamp, "Morality and the Social Control of Biomedical Technology," in W. B. Bondeson et al. (eds.), New Knowledge in the Biomedical Sciences (Amsterdam: D. Reidel, 1982), pp. 55-75.

³⁰Ibid., p. 370.

³¹Cf. R. W. Evans, The National Heart Transplantation Study, Chapters 23-26; M. Buxton, Costs and Benefits of the Heart Transplant Programmes at Harefield and Papworth Hospitals, Chapter 9.

³²D. Dutton, Dilemmas in Medical Progress, Chapter 1, p. 30.

CHAPTER IV

THE MEANING OF TIME

It requires a certain daring to attempt a simple explanation of Christianity's legacy to western culture. The image of religion in our society is one of considerable disarray. The introduction of this paper was a summary of the limitations which anyone working from within the Christian tradition must observe if he wishes to enter the dialogue that constitutes the world of bioethics.¹ The purpose of this chapter is to develop a working concept of Christianity which is definitive in two ways:

1. It does reasonable justice to the institutional and theological reality of Christianity;
2. It offers a basis for entering the conversation and development of bioethics as an influential partner, able to contribute to the product which emerges.

What sort of ground rules will this demand?

1. A stance as to the desirability of pluralism as a principal characteristic of moral climate. Is this a phenomenon which is to be tolerated merely as a temporary departure from the ideal, or is it an opportunity for the extension of rationality to an enlarging vision of human

community? By the latter, we mean a renunciation of the imperialistic and colonialistic versions of unity in favour of those which explore the potential for understanding found in language and rational dialogue. Would the acceptance of pluralism and the consequences thereof constitute abrogation of the fundamental principles of Christianity?²

2. Agreement that religious expression is not outmoded, but a persisting reflection of human cultural perspective with a separable but not distinct claim to participation in the rational world of human creativity.

3. Acknowledging that it is extremely difficult to retain control over ideas and principles in the open cultural and intellectual market of today unless they are in the form of dogma or ideological orthodoxy. Even here, to take one example, Marxian social analysis is not the exclusive property of the communist world as is exhibited in the appearance of liberation theology in Christian circles. This reservation is extremely important because it modifies considerably the value of a concept like secularization as a way of understanding the dynamics of intellectual ferment at the present time. We believe the term places an emphasis upon a relationship between ideas and society which gives too much priority to the influence of the individual.

4. For essentially the same reasons we have just noted, this may mean that the seminal role given to ideas in producing change in our human world must be qualified by an appreciation of the potential of alterations in the structural form of

social culture for inducing major transformations in human values.³ In this context what follows will be somewhat indebted to the theories of Anthony Giddens and Jürgen Habermas.

If we try to apply these rules to formulate an answer to the ~~question~~ "What is Christianity?", a number of useful observations may emerge as to its legacy for the current debate about norms and values in bioethics.

Christianity is one of many traditions by which human kind lives. This follows from a more general understanding that to be human is to live in a tradition, regardless of the fact that at any given time many people are in open rebellion against tradition and even reject it altogether. The intelligibility of speech is possible because the structure and meaning of particular sounds is handed down from those who have shared this experience. Much of the learning which makes up human knowledge is passed on through being part of a tradition. In modern culture, it is often the case that persons belong to several traditions at the same time -- they have many centers to their lives. One of the more important conditions imposed by contemporary culture is that of finding ways to facilitate communication between these several centers which are found in every person. The bias of modern thought was originally committed to an exclusively verbal and rational model of communication between these foci of meaning. Those forms of experience, such as religion which attempted to mediate between the verbal and non-verbal structures of

meaning tended to be discounted in the original rush to substantiate instrumentally the verbal and rational. The stance of Christianity can be viewed historically as an attempt to balance ritual and symbol with the verbal and rational.

Our particular interest is the manner in which Christianity has attempted to give expression to moral values and ethical consequences.

1. Most accounts of early Christianity have concentrated upon the struggle to establish orthodoxy in the face of fulminations by those who would divert the movement from its central focus. The early centuries of the Church led to the emergence of a series of "doctrines" which established the forms to which faith and its rational expression were directed.

The social expression of Christianity rapidly evolved from its early base in the synagogues of diaspora Judaism into an institutional structure called the Church. One of the most important influences on this development was the particular way in which Christians understood the eschatological ideas which emerged from the mood of the times, the sayings of Jesus, the early writings which became scriptural, the social experience of its adherents, and the reflection upon all of the above in the works of its early leaders. The merger of these elements produced an understanding of reality which included "two worlds" that eventually were resolved into the Augustinian civitas dei, and civitas terrena. One of the favorite ways of summarizing the effect of the otherworldly resolution to this world's end was the saying "in but not of

the world." This view was to have considerable effect upon the way in which the Church set upon determining its priorities. The result of most interest to us was that felt upon morality and ethics.

2. There is no way here of resolving all of the issues raised by any discussion of the ethics which arise from Jesus' preaching as recorded in the Gospels. We have decided to adopt as our approach to these problems several working principles which should give an acceptable result. Christ's purpose was to create a community of those who were ready for the coming of the "Kingdom of God." His ethical ideal arose out of the moral demands for the sanctification of the individual so that he might be able when the "time comes" to "see God."⁴ The extreme form of purity of heart which He demanded had its major emphasis upon intention which comes from "a greatly intensified reverence for all moral commands, without any allowance for conflicting motives or for expediency."⁵ The final object for all moral conduct was a personal relationship with God whose imperative was a function of the soul, something each person possessed. It is necessary to insist, as well, that while the Gospel may not result in a complete or systematic ethical system it does not issue in a merely subjective authorization for independent exercise of conscience. "... the ethic of the Gospel deals not merely with the will and its intention, or with the inner constraint of conscience, but also with certain definite concrete demands."⁶ The view of the Gospel ethic set in concrete terms is that God

is the very center of all moral purpose.

All the virtues, therefore, are thoroughly systematized from the fundamental religious point of view: union with the Will and the Being of God, and cooperation with the work of God.

It is within this constraint that Christ required human kind to be indifferent to material happiness and to money, to practice sexual self-restraint, to have a mind that values the unseen and eternal more than the seen and temporal and to strive toward a harmonious sense of personal being.⁸

3. The ethical structure of the Gospels is not the sole item in the development of Christian attitudes. Almost immediately in point of time it existed as one element in a dynamic; the other part was the community of those who "shared" this vision. It was probably Troeltsch who first called attention to the unusual character of this social structure, but others have made similar observations.⁹

Its first outstanding characteristic is an unlimited, unqualified individualism. The standard of this individualism is wholly self contained, determined simply by its own sense of that which will further its consecration to God

It is clear that an individualism of this kind is entirely radical, and that it transcends all natural barriers and differences, through the idea of the religious value of the soul

Where this kind of individualism prevails all earthly differences are swallowed up in the Divine power and love which reduce all other distinctions to nothing

From the very onset this was not an ideal for the masses. Faced by the extreme tension of these demands, we must also remember that they were formulated in expectation of the final Judgment of the imminent End of the World. However little these demands may have been due to this expectation, we

must realize that their radicalism and their indifference towards questions of practicality can only be understood from this point of view¹⁰

Also present within this individualism is a powerful ideal of fellowship which has the potential for translating into a special understanding of community. This is discussed by Troeltsch as Universalism of the same all-pervasive religious mode. For the moment, however, it is more important to show that this fellowship arises out of the same equally powerful religious motive which is present in "Christian" individualism.

In the last resort the idea of fellowship springs from the fact that those who are being purified for the sake of God meet in Him; and since the dominating thought of God is not that of peaceful happiness into which souls are gathered but a creative will, so those who are united in God must be inspired by the Will and Spirit of God, and must actively fulfil the loving Will of God.

... this is the background and meaning of the Gospel emphasis on brotherhood and the love of one's neighbour ... But this fellowship only extends as far as the religious message is known ... There is no thought here of a humanitarian ideal in itself. When the effort to establish this fellowship fails the Gospel only can exhort to suffering and patience, until the judgment will set things right. Here again, in order to understand Jesus' exhortations, we have to remember that this restoration is not thought of as taking place after a long life in the world, but after a short period of time.¹¹

There are other forms of this same insight which may be relevant to our case. The most significant may be the Pauline metaphor of the mystical body of Christ.¹² While containing all of the elements noted above it had the additional advantage (as we see it now) of offering a mode of expression which was more adaptable to the sociological needs

that arose as the expectation of Jesus' imminent return faded. Why this should be the case may emerge when we consider another issue -- that of power and authority.

4. What seems necessary to explain is how God is known and how his power is mediated to that which is other than Himself.

For Jesus according to Troeltsch:

The Idea of God bears both the features of a fatherly loving-kindness which calls all to the highest dignity of life, and also of a perfection which maintains souls always in humility, and yet ever encourages them through the forgiveness of sins. It does not, therefore, represent itself as an inevitable idea, but as authority and revelation. The Hebrew God of Will, in his aloofness from mankind, only makes Himself known in living revelation in the Law and in the Prophets, and in the authority with which Jesus interprets both. In this way the idea of authority is introduced into the sociological structure. The whole system of thought which has just been described arises out of faith in an authority of this kind, and the securing of this authority as its essential source will be a permanent task of the whole structure.¹³

If we were to try to visualize the system just developed laid out on a map, imagine what is present and absent. What kind of a geography of reality springs to our eyes? The cartography is rich in showing numerous details about human kind as a social being which must at the same time try to keep track of those aspects of its character which make understanding human actions so perplexing. Almost completely absent is any suggestion of humanity's simultaneous inclusion in the world of nature. Knowledge of this latter condition is unimportant possibly because it is essentially unobtainable. The next question which must be asked is whether or not this blank is to be temporary or permanent.

The answer can only be given in somewhat roundabout fashion. This is because it is dependent upon the potential for growth and change which is in the community that resulted from Jesus' preaching. The elements which were used to nourish this development form another major variable. An organized community which became increasingly sophisticated in theory and structure appeared quite soon after the death of Jesus. It appears to have been somewhat different in form from the primitive communal groups which are noted in the Acts and the Letters whose interest has been described as religious Communism of Love.¹⁴ That this loose organization was unsuited to the needs for a structure able to work and grow beyond the interests of tiny local communities seems probable. This would seem to have led to a need to find additional ethical content more appropriate for an institution which claimed to be the living body of Christ. It required some way of connecting itself to the work and purposes of its head. One possible form in which this might be manageable was that of directing the salvation of souls.¹⁵ This was a reasonable substitute for the condition of readiness which Jesus held up as required for those who would see God on his return at a time close at hand. Physical death now becomes the End which Jesus anticipated and for which life of whatever length becomes the time of preparation -- the opportunity for repentance. In acknowledging there was now "time" for salvation, Christianity had also created the opportunity for doing other things as well. Interest then

shifted towards an exploration of possible sources of inspiration which might be relevant for the conditions at hand. Scripture had an obvious claim because it had been authoritative for Jesus, but increasingly the intellectual riches of the classical world began to be mined as well.

Together they helped create a view of nature which filled in the gaps that existed in the world view of Jesus and his immediate followers.

We offer the following account of the kind of development which seems to have taken place.

1. As Christianity began to acknowledge that it would have to live apparently for some time under the conditions of the existing world, it became necessary to adjust its organization and theology to the social and legal structures which were in force. What it required was "a general theory of the basis and validity of the 'laws' which the Christians could accept."¹⁶

It was the role of the Apologists, who not only fused the ethics of Christianity and Stoicism but also made the first attempt to bring the laws of the City of God into some kind of Harmony with the laws of the city of this world.¹⁷ The vehicle for accomplishing this feat was a development of the concept of Natural Law. The efforts were no doubt dependent, at least initially, upon ideas provided by Stoic writers on this subject.

2. While the original intent of the Apologists was more directly ethical there was extensive spill-over of these ideas into the realm of those which were used to understand

and explain nature. There existed then, from the earliest centuries of Christian thought a body of material which ventured into the intellectual world of science.¹⁸ Both ethics and science were understood to be concerned with the discovery and presentation of the workings of the Natural Law which itself was a reflection of the domination of Divine Reason over the affairs of man and nature. In effect, this meant that Christian ethics and Christian science were committed to a course of development which was based upon deduction. Their assumption of the rationality of the universe made no other outcome likely.¹⁹

This does not mean that observation was totally absent from Aristotelian and medieval science. Many of their conclusions were in conformity with common experience. Aristotle had done considerable biological classification, which required careful observation. But the categories of teleology (purpose) did not in general lend themselves to "theories" that could be tested by further "experiment."²⁰

3. Since there was a strong tendency to view the world as functioning according to law there was a tendency to concentrate on the static nature of the structure upon which it depended. The perfection in the mind of God was reflected in the manifestation of his creation. This led to a view of nature and of man which was essentially fixed because creation had produced a completed world in which there could be no fundamental novelty except as was determined by God's direct action.²¹ Most interpretation of the so-called medieval legacy has focused upon the concept of the world, as static as providing the most direct opposition to the new

theories of science, first introduced by Galileo and brought to first perfection in the seventeenth century with Isaac Newton. Further reflection, however, suggests that another understanding of the nature of this law-reflecting world is more productive for understanding current problems facing the ethicist who would be Christian. Barbour has more correctly identified the issue: "It was a 'law-abiding world', but the laws were moral and not mechanical. This was the medieval view of the universe which the new science was to challenge."²²

4. The escape from Natural Law has come to completion in the science of the nineteenth and twentieth centuries, beginning with Darwin, and extending to Einstein and theoretical physicists. There is, first of all, the replacement of the mechanical model for understanding the working of regularity in nature. This change may be expressed as the challenge to the assumption that the natural tendency of reason is to express itself only in "law" or law-like statements or principles. This observation is devastating in its effect upon the social structures which have grown up making this supposition. Not only is one of the favorite grounds for religious ethics left in disarray but also the value structure used to rationalize the social desirability of science is undermined. The full meaning of what is implied in postulating moral neutrality for science is now unfolded. It further raises the possibility for arguing that the dilemmas facing both ethics and science today have a common origin and that therefore it may be fruitful to pursue an examination of

other rational models of understanding common to religion and science.

5. Barbour puts forward three presuppositions about nature which are important to modern science and suggests that they are compatible with sentiments found in the Christian doctrine of creation. First, there is the conviction about the intelligibility of nature.²³ Strictly speaking, the religious component of this notion is primarily in terms of the universality of order and coherence, but that this may have important effects upon the development of modern science is argued by Whitehead:

I do not think, however, that I have even yet brought out the greatest contribution of medievalism to the formation of the scientific movement. I mean the unexpugnable belief that every detailed occurrence can be correlated with its antecedents in a perfectly definite manner, exemplifying general principles When we compare the tone of thought in Europe with the attitude of other civilizations when left to themselves, there seems but one source for its origin. It must have come from the medieval insistence on the rationality of God, conceived as with the personal energy of Jehovah and with the rationality of a Greek philosopher In Asia, the conceptions of God were of a being who was either too arbitrary or too impersonal for such ideas to have much effect on instinctive habits of mind My explanation is that the faith in the possibility of science, generated antecedently to the development of modern scientific theory, is an unconscious derivative from medieval theology.²⁴

There is also the belief that the details of nature may be known only by observing them.²⁵ In Christian thinking this is implied in the idea that since creation is the product of God's free act, He did not have to make it exactly as He did and we can understand it only by actually observing

what is there.²⁶ The universe is contingent on God's will which means that it is not a necessary consequence of first principles -- it is contingent and orderly, because God is both free and rational. Christian reason has tended to stress proceeding by analogy which means making use of finite objects which imperfectly illustrate their form, while the earlier effects of Greek thought was to emphasize the grasping of the whole through an intuitive perception of its essence.

Finally, we note its affirmative attitude toward nature which springs from the creation story in Genesis and is developed in a multitude of themes in the rest of Scripture. There is in addition, the stories which depict the defeat of the Nature Gods by Jahweh²⁷, which determine that the world of nature being created was not a proper object of worship but did leave open the possibility that it might become the fitting subject of study.²⁸ The conditions which made possible the scientific revolution were obviously complex and the result of much more than its root in the biblical view of nature. Nonetheless,

(c)ould the recognition of statistical regularities and their mathematical expression have been reached by any other road than the theological one we actually travelled? The only test comparison with a developed civilization is that of nontheological China. As Needham and Northrop have remarked, theology in China had been so depersonalized, law made so ethical, humanistic and particular, that the idea of a rational creator of all things was not formulated. Hence the idea that we lesser rational beings, might by virtue of the Godlike rationality, be able to decipher the laws of nature (in Galileo's

phrase, we might read the mathematical language of the Book of Nature) never was accepted.²⁹

How can this analysis help us to clarify the opportunities for Christian thought to current ethical concerns? We can begin by noting the extent to which Time, and how to account for it emerged as an increasingly difficult problem for Christianity. We have already seen how Jesus developed his ethics in terms which anticipated their validation in a final judgment which was to come very soon. Other writers who appear in the New Testament including Paul appear to have much the same attitude³⁰ but they were left with the task of giving responsible advice to the communities which had sprung up in Jesus' name. A limited but certain practicality marked their approach³¹ which was continued after the Apostolic period particularly during those times when the Roman state was tolerant of this Christian presence. Even the long term effect of the periods of persecution did not alter appreciably the attitudes of the Church towards the requirements for order and structure which were necessary for its continued well being,³² and which it was prepared to claim were the same for any decent society. In doing this, it needed to designate some measure which would mark the boundaries of human power and knowledge. The direction taken appeared at first to be a simple development from the Jewish tradition of responsibility as respect for divine commandments embodied in The Law. However, it introduced a modification of the way this system operated in its insistence

that there was a major gulf between Law and Gospel which was based upon the content of Jesus' preaching and life.³³

Christians were law abiding citizens who because of their citizenship in the Kingdom of God were free in the way that God was also not bound. Initially at least, the issue was not their perfection, but their freedom which was ultimately a reflection of the fact that they were not held by the time of this world but were open to live in the life which was to come.

The Church through the sacraments became the broker in this system which eventually was able to measure and thus calculate the condition of one's current and future states of existence. Paul Tillich was deliberate in his choice of the term economic to describe the system created.³⁴ We have here an attempt to bring together the divine and human households that they might have common activity within the dispensation of creation. At least since the time of Aristotle, there had been a secular science of economics. What the church was trying to attempt was a policy not unlike joint management! Substantiation for this claim may be found in the curious combination of language relating God and the Church and found in both the Bible and later writings. We detect a fascinating alteration between regal and homely terminology, of hearth and home and royal dominion, a covenantal relationship which allows for remarkable versatility for both parties. The audacity of this view was mind boggling particularly as it led to a banking system for calculating the state of one's

soul as a function of time; and while the Reformers, notably Luther, detected that the violations resulting from trafficking in indulgences were a negation of the very meaning of Grace,³⁵ it is interesting to note that Calvin and his followers also totally rejected the structure of salvation which was erected by the Catholic tradition, but retained the practice of calculation as it applied to one's status in the divine economy. Called by Weber, "wordly asceticism," this attitude proclaimed that one's wordly success was a reflection of divine election, and hence life was to be lived with this grave responsibility clearly in mind.

This theological conflict need not be viewed merely as an artifact of the age of superstition because it does stand as a monumental attempt at introducing methods of calculation into the difficult area of valuing human action in terms which try to take into account a longitudinal perspective of both space and time. What strikes one as problematic is the effect of this attempt which in the same breath negates real time and space no matter how brilliant we might regard Dante's Purgatorio. On the other hand, it does mean that we need not regard a utilitarian stance as a requisite for entering into the exercise of calculating value. The success of Calvin's ethic makes this point loud and clear. What seems to be missing in these attempts is a sufficient perspective which makes calculation the determinative act it generally is; and allows also for a more complex approach to the space and time setting of the known world, i.e. creation.

James Gustafson has put forward an interpretation of the world which reworks a number of the biblical symbols and their theological construal in a way which may contribute to a construction of ethical activity in bio-medicine. He notes that Claus Westerman has suggested that the imagery of Genesis 1-11 implies that: "The surroundings sustain the life of the human community, and that part of the problem of human living is to be appropriately related to our surroundings."³⁶ It is recognized that included in human capacities is the ability to develop which has come to be known as culture which includes also the establishment of cities (Genesis 4:17, the development of nomadic life [4:20], music [4:21], and technology [4:22]). On all of these occasions human kind is shown to have an interrelationship with nature and other persons and thus is always acting in response to what is found in the world.³⁷ This suggests, concludes Gustafson:

Religious affectivity is evoked by objects of experience, and in the religious consciousness of the Western religious traditions this evokes piety toward manifold powers and toward the powerful Other that is perceived to be present in and through the world.³⁸

From this he feels it possible to argue that:

"Objects" experienced by persons early in the tradition were responded to in religiously affective ways and led to the theological construing of the world that symbolized the power and the powers in the name of God as the Creator. There are similarities between our experiences of our surroundings and those described in these narratives: our surroundings evoke similar sense, attitudes and dispositions, and affections. The world is not "in human hands"; we also depend upon and respond to many things that are given both as limits and as possibilities for our species. No Eden is given to us, but we receive the natural world, culture and society of our own times.³⁹

Since our attempt is one which is seeking to understand the norms governing action, it may be helpful to try to be more specific as to how God's activity is to be construed. Again, referring to Gustafson, we note the distinction between the sustaining of life through ordering as well as with creative powers and capacities. There are many ways of observing a mode of governance at work in the world. For example, continuities in the genetic code make possible the replication from generation to generation of creatures who have the capacities we recognize as human.⁴⁰ But, however we acknowledge the existence of prerequisites which must be respected and tended if life is to continue, this must not be extended to a claim that there is a clear and unambiguous "telos" in the mind of God upon which a moral purpose for creation exists, particularly one which a warrant for the domination and continuation of a single species may be postulated.⁴¹ What may be more important to ask is the importance which the discernment of divine sustenance and governance in the prerequisites and necessary conditions for life has for contributing to a discussion about the ethical considerations appropriate for the use of high technology. The most crucial distinction may result from deciding how we are to understand that what we know about the ordering which is at work is dependent upon the state of knowledge which is present at a particular time. Obviously this knowledge both limits possibilities and make possible cooperation with it and introduces the circumstances upon which new developments

arise. But is the only source of limitation that which is produced by this state?

1. To begin with we must acknowledge that the limits of knowledge apply to morality as well.

Morality in this perspective is the task of discerning what the divine ordering requires under particular conditions in a particular time and place. It is not a task of knowing what the immutable divine moral order of the universe is and then developing institutions and human relations to conform to it.⁴²

At the same time the Christian perspective puts forward the concept that there is a changing but permanent horizon of limitations which is expressed in the signs of governing and ordering in the world -- whatever the current state of knowledge.

2. How we perceive our own "time" is a major determinant of our behaviour particularly in terms of the sense of responsibility which results. Particularly significant in this connection is the sense which we have of tomorrow.

3. The preaching of Jesus produced in the Christian community a sense of tomorrow as the Day of Judgment and makes today an occasion for which one must be prepared to answer, or for which one must accept responsibility.

4. The knowledge content of morality as it applies to the human activity of technology relates quite specifically to the claims which may be made at any particular time to the resources that are present on the earth. Our present understanding is that they are limited and thus the continuation of life must respect the current information which is

available.

5. Time compromises the way in which we regard the moral implications of technological activity because it presents both the effects of past knowledge and the commitment to future existence.

6. It is possible to recognize more than one function or vocation for the Christian community in society. It is a gathering of those who are called into being as a response to the life and work of Jesus the Messiah. Its primary loyalty and devotion, which is expressed in being gathered together as worshippers, is to God who creates, sustains and governs.

"Not only is dependence on the divine ordering acknowledged but also the accountability to it. God as Sustainer and Governor remains a powerful religious symbol."⁴³ It acknowledges as one of the conditions of its existence a duty to participate in the life and future of the whole human community as well. In doing so it accepts responsibility for helping to create a language of morality which expresses consent and acceptance of those limits to action which it knows as Divine Governance.

Obviously there has occurred a rearrangement of the usual style of moral argument, a reversal of the roles traditionally given to religion and science. What we have learned is that understanding of what we cannot do is highly dependent upon the current state of knowledge. What we learn also is that there is a need to project this sense of

limitation into the future in a way which leaves open the possibility for others to have the same opportunity.⁴⁴

Footnotes to Chapter IV

¹Cf. Introduction, especially p. 3ff.

²Jurgen Habermas, "The Hermeneutic Claim to Universality," in Josef Bleicher (ed.), Contemporary Hermeneutics: Hermeneutics as Method, Philosophy and Critique (London and Boston: Rutledge Keegan Paul, 1980), pp. 181-209; Thomas McCarthy, The Critical Theory of Jurgen Habermas, pp. 169ff; Charles Taylor, "Interpretation and the Sciences of Man," Review of Metaphysics, Vol. 25, 1971, pp. 3-34; 45-51.

³As an illustration we have in mind the increasing skepticism which has followed upon Kuhn's change of paradigm concept to account for change in scientific understanding of nature.

⁴Ernst Troeltsch, The Social Teaching of the Christian Churches, Vol. I, translated by Olive Wyon (New York: Harper Torchbook, 1960), pp. 51-52.

⁵Ibid., p. 52.

⁶Ibid., p. 53.

⁷Ibid., p. 53.

⁸Ibid., p. 54.

⁹Cf. Karl Adam, The Spirit of Catholicism, translated by Justin McCann (New York: Image Books, 1954), Chapter 2 and 3.

¹⁰Ernst Troeltsch, The Social Teaching of the Christian Church, Vol. I, p. 55.

¹¹Ibid., pp. 56-57.

¹²viz. I Corinthians, Chapter 10.

¹³Ernst Troeltsch, The Social Teaching of the Christian Churches, Vol. I, p. 58.

¹⁴Ibid., p. 62.

¹⁵ Ibid., p. 63.

¹⁶ Ibid., p. 150.

¹⁷ Ibid., p. 150 n. p. 192.

¹⁸ Ibid., p. 142.

¹⁹ Cf. R. Barbour, Issues in Science and Religion, p. 17.

²⁰ Ibid., p. 18.

²¹ Ibid., p. 19.

²² Ibid., p. 18.

²³ Ibid., p. 46.

²⁴ A. N. Whitehead, Science and the Modern World (Cambridge, England: Cambridge University Press, 1928), pp. 13-14; quoted by R. Barbour, Issues in Science and Religion, p. 46.

²⁵ Ibid., p. 46.

²⁶ Ibid., p. 46.

²⁷ Ibid., p. 47.

²⁸ Ibid., p. 47.

²⁹ R. Cohen, "Alternative Interpretations of the History of Science, in P. Frank, Validation of Scientific Theories (Boston: Beacon Press, 1954) from R. Barbour, Issues in Science and Religion, p. 48:

³⁰ E.g. I. Thessalonians.

³¹ Notably in the Council of Jerusalem described in Acts 15.

³² Ernst Troeltsch, The Social Teaching of the Christian Churches, Vol. I, p. 112.

³³ Cf. Romans, Chapters 1-8.

³⁴P. Tillich, Lectures on the History of Christian Doctrine, New York, privately printed, Union Theological Seminary, 1953, p. 46.

³⁵Particularly offensive was the jingle used by Tetzl: "As soon as the coin in the coffer rings, The soul from purgatory springs." This triggered the 95 Thesis on the Eve of All Saints, 1517. R. Bainton, Here I Stand (New York: Abingdon-Cokesbury, 1950), pp. 77-79.

³⁶Claus Westerman, Creation, translated by John J. Sulfivan, S. J. (Philadelphia: Fortress Press, 1974); c.f. Gustafson, Ethics From a Theocentric Perspective, I, p. 237.

³⁷Ibid., p. 237.

³⁸Ibid., p. 237.

³⁹Ibid., pp. 237-238.

⁴⁰Ibid., p. 239.

⁴¹Ibid., p. 240.

⁴²Ibid., p. 242.

⁴³Ibid., p. 242.

⁴⁴James Gustafson, Ethics From a Theocentric Perspective, Vol. I, p. 81; Hans Jonas, The Imperative of Responsibility, Chapter 5.

CHAPTER V

TRADING TIME

To allow modern medical technology to be managed with both humanistic perception and scientific effectiveness, the basic strategies must come from a clinical scholarship that is rooted in the care of patients, aimed at the care of patients, and based on data and models that reflect the pertinent observations, events and care. The scholarship should be broad, wide-ranging, and receptive enough to include and apply the many valuable contributions that come from other basic domains.¹

The most difficult decisions which are taken in the application of high technology medicine are those involving the selection of patients. These judgments require the assessment of a great deal of clinical evidence and require us to consider how physicians accumulate and assess what is believed to be the relevant material for arriving at a diagnosis or prognosis. We think it not unfair to term this the search for the "right" patient because there is some reason to believe that the success of many high technologies is dependent upon finding those most likely to respond to treatment. This practice was evident in the development of the Stanford criteria for selecting persons for heart transplantation following the general moratorium on this procedure. Interestingly enough, high technology seems to find the human element a factor worth considering in its search

for relevant variables, and again this is noticeable in the inclusion of psycho-social criteria in the Stanford protocol. What is also important to notice is that two other levels of management are now partners in the selection process: those of the health care institution and that of government. We shall begin this section with an examination of the methodology of decision-making showing how it affects the selection of patients for high technology treatment; and then turn to a description of the possible roles of institutions and governments in determining the right patient.

As a result of being a participant-observer in a heart transplant selection team for the past three years,² we have found it helpful for purposes of understanding the process of clinical decision-making to view each patient as a "construct."³ This is because in this process each patient plays several roles which are factored by clinicians into the data considered to be relevant for determining his suitability. He is, whenever possible, a partner in the decision itself, since he is regarded as an autonomous individual. He is the major source of the data that will be used to determine his fate. He is a suppliant in need of help with the voluntary nature of this position assumed, even if he is unable to say as much. He is increasingly an unequal participant in the planning of his future which depends upon knowledge that is too complex for him to comprehend fully. How he "reacts" to all of the above is deemed of considerable importance for the outcome of the process of treatment, and

the subject of intense prognostic debate. We shall examine each of these persona in detail, in order to show how each one becomes incorporated into the decision-making process.

Autonomy is widely acknowledged to be one of the principles upon which western political and social values are ordered. It is often seen as indispensable to the existence of large scale democratic government and industrial development. It has had, however, a somewhat checkered role in the value structure of western medicine in which beneficence and paternalism have tended to dominate. Historically, we can account for the authority of these latter principles as arising out of the demands made upon doctor and patient to behave according to the pattern which respected the proper role (virtues) of each party. There has tended to be a certain inequality in the relationship between doctor and patient with Hippocrates often being given credit for establishing the model. This traditional imbalance seems to follow the course of a society which was accustomed to a natural hierarchy of orders and roles and produced a view of moral responsibility which reflected this. The good or virtuous patient was one who followed the physician's orders which were based upon a determination of the derangement of the natural order which he had observed in the patient.

What transpired between the doctor and patient did not require the participation of the patient as a decision-maker, but it did not necessarily preclude the patient's knowing the truth about his condition, particularly if death were close

at hand. Indeed as the Spanish medical historian, Pedro Lain Entralgo has suggested, Hippocrates was responsible for the counsel that no verbal communication between the patient and his physician should take place.⁴ Completely absent is the notion that the appropriate relationship is a function of rights and obligations as they have been interpreted in political terms since the eighteenth century and as indispensable philosophical principles since about the same time. What remains to be determined are the circumstances which have brought to the doctor/patient relationship these political and philosophical concepts.

One of these is the increased ability of medicine to respond in more than one way to the ravages of disease as it effects the individual person. Though there is now a greater element of choice available to both physician and patient, this is not in itself a sufficient cause for the demand for patient participation in decision-making, as is evidenced in its general absence from the practice of high technology medicine in Europe.⁵ For North Americans, something decisive has happened to the manner in which people or persons are construed as moral and social beings. Life has become atomized, meaning that social and moral relationships are viewed as dependent upon rights and obligations deliberately contracted.⁶ For this to be possible, it is necessary to assume that all persons are in a more or less permanent state of rationality and competency. The effect of this idea upon the practice of medicine can be seen in court decisions which

have been handed down in recent years in both the United States and Canada. In 1972 the United States Supreme Court concluded:

To bind the disclosure obligation to medical usage is to arrogate the decision on revelation to the physician alone. Respect for the patient's right of self-determination on particular therapy demands a standard set by law for physicians rather than one which physician's may or may not impose on themselves The patient's right of self-decision is the measure of the physician's duty to reveal.⁷

The result is that moral protection in the sense of respect due a person, becomes knowledge dependent; because it is tied to the information that a reasonable person, in the patient's or subject's circumstances, should find relevant and be expected to assimilate. Effectively this makes additional moral protection a function of the stringency of disclosure requirements and the Courts seem inclined to opt for more and more disclosure as sign of the physician's moral responsibility or the patient's moral worth. The recent case in Saskatchewan is a good example of this tendency.⁸ Such an objective view of rights seems to restrict unduly any sense of the nature of physician responsibility to persons conceived as real, live "patients." Suggestions have been made to tailor the reasonable person standard to the needs of the individual patient, i.e. introduce subjective standards for acknowledging the individual requirements for information as one way of modifying this rigid caricature.⁹ Such proposals do little to challenge the ideology that a patient can be accurately depicted as a fully autonomous being, for under

these terms the only alternative is to find him incompetent.

When we turn to the next element in our construct -- the patient as a source of "data" we enter into the set of calculations which is most uniquely illustrative of medical reason. It takes very little time on a hospital service to discover that a great deal of emphasis is placed upon the necessity for having "hard" data in order to facilitate the scientific character of medicine. What is meant is the availability of documentary information which has the qualities demanded by scientific evidence. Material of this kind is most frequently obtained from laboratory tests which may be preserved (provided they are found in the first place) and thus checked or repeated. The information revealed is of a kind now generally called pathophysiology.¹⁰ It is the result of objective observation and expressed in terms of dimensional number.¹¹

There is, in addition, a great deal of knowledge about a patient which is the product of clinical observations. It is labeled "soft" data mostly because of the terms in which it is expressed. Examples of this information would include:

The type, severity and sequence of symptoms; rate of progression of the illness; severity of comorbidity; problems of functions capacity; reasons for medical decisions; problems in maintaining therapy; impact of both ailment and treatment on familial and interpersonal relationships; and many other aspects of the physical activities, joys and sorrows of daily life.¹²

It has been made clear that information of this soft variety plays an important role in both the screening and selection of candidates for heart transplantation.¹³ Unfortunately,

with the possibility of quality of life studies on pre- and post-transplant patients,¹⁴ this knowledge is not easily transmittable to anyone wishing to know whether or not it provides crucial "data" about heart transplant patients.

It may be helpful therefore, to examine more closely the effects of classifying information as to its "hardness" or "softness" because:

1. A great deal has been made of the fact that a scientifically based medicine must be based upon the use of "hard" data.

2. An equally strong point has been made that the values inherent in a humanistically focused understanding of human kind are by their very nature resistant to a classification system which reduces them to mathematical relationships.

3. The case continues to be made that we wish:

To become masters rather than slaves of technology by expanding it to include human data, by aiming at human goals and by making it respond to human aspirations. The complexity of human beings is what creates the current dilemma, but also provides the human brains that can help resolve the dilemma.¹⁵

4. At the same time, it is unclear what contribution to improved decision-making an expansion of the information base to include soft data will make.

5. It is also in order to ask what effect the conversion of soft data into some form of objective measure will have upon the way in which we view the knowledge so affected.

But if we accept the view that optimum use of technology requires selecting the best patients to receive its

ministrations, then it is possible to understand why several proposals have been made for introducing as variables in the decision-making process objective readings of those elements identified as personal and humanistic. They could offer new parameters that are important to the welfare of the patient because:

1. Within a given diagnostic category, the actual disease process is not static but highly dynamic and closely related to the individuality of the person affected. Yet the flow-sheet format which is used frequently to manage the important information about a patient rarely includes important elements of knowledge such as the severity of his disease, his functional status or psychosocial dynamics.¹⁶ Interestingly enough, this information is a subject of constant review by the clinical staff but remains essentially anecdotal and therefore indifferently preserved.¹⁷
2. Prognosis is not a simple derivative but a result of complex interactions and not very much is known about how to go about it:

To manage the powerful therapeutic agents concomitantly produced by the technologic advances the clinician's main scientific challenge in disease today has become prognosis rather than diagnosis. To make effective choices among the multiple therapeutic possibilities, clinicians must be able to predict the different outcomes for patients in distinctive, different groups (or stages) of the spectrum of each disease and to evaluate the effect of treatment in each prognostic group.

Yet prognosis has been given relatively little scientific attention.¹⁸

Striking evidence of the kind of debate which can ensue when there is disagreement about prognosis can be found in a

letter in Lancet:

The report from the Council of the British Cardiac Society (1984: 52: 679-82) quotes the Stanford experience and gives the one and five year survival figures of 63% and 39% respectively. Interestingly, these figures are virtually identical with the survival rates for a group of 169 patients with dilated cardiomyopathy (the principal indication for cardiac transplantation) who were treated medically at Hammersmith Hospital. The one year and five year mortality rates of that group were reported to the British Cardiac Society as 34.7% and 59.4% respectively.

Council's suggestion that cardiac transplantation prolongs life, is on this evidence difficult to accept, particularly in view of the fact that on an "intention to treat" basis the surgical survival figures would be considerably worse -- that is, because of the high mortality in the sizeable group of very sick patients who did not survive long enough to get a transplant.¹⁹

3. It may be that a transformation of soft data into hard may provide information that will improve the results of attempts to predict the future progress of a disease. Many feel that it will be the way to gain intellectual respect for this important clinical information. If this is possible, then attempts must be made to standardize the forms of expressing the material, and to develop uniform rating scales and indices. Alvan Feinstein has anticipated some of the reservations that could be held about such efforts:

... defenders of current paradigms about the ability of scientific data may claim that subjective observations, verbal descriptions, and nondimensional scales can never be scientifically adequate and that clinical mensuration will best be improved with research concentrating on technologic procedures. For example, the technology now developed for precise dimensional measurement of urinary sugar levels is surely superior to the clinometric method 2 centuries ago when physicians tasted the urine for sweetness.

This argument can be answered in two ways. First, the technologic success that was achieved in measuring

tangible substances such as sugar in urine, cannot be expected for such nontangible, subjectively perceived sensations such as pain, discomfort, distress, anxiety, fear, love, hate, joy and sorrow. The more distinctly human and intangible a phenomena is, the more distinctly human will be the observational system needed to identify it. Secondly, even when technologic measurements seem to correspond directly to the observed clinical phenomena -- such as pulmonary function tests for dyspnea, and exercise stress tests for functional capacity -- the actual correlations are often unsatisfactory because the laboratory conditions of measurement do not suitably simulate the diverse challenges encountered in daily life.

Yet another type of opposition to clinometrics may come from defenders of clinical "art," who fear that this new science will further dehumanize clinical medicine. ... In fact, a system for precise identification and classification can help rehumanize important clinical phenomena because medical students, house staff, and practicing physicians will have to pay attention to the patient whose statements, comments and other clinical data are needed to supply the basic information.

... if clinical information has no value beyond sentimentality, neither students nor physicians can continue wasting time to acquire the data. If the information does indeed have major values, however, the values should be identified, specified and analyzed.²⁰

4. The effect of this additional data will be to increase substantially the multiple variables that must be accounted for in arriving at a medical decision:

After obtaining an enormous amount of multivariate information from history taking, physical examination, paraclinical tests, managerial interventions and patient's outcomes, clinicians process the data intellectually in diverse ways to arrive at decisions that are expressed as diagnoses, prognostic estimates, therapeutic choices, posttherapeutic evaluations, and statements of communication or reassurance.²¹

But is it really possible to process all this information and to arrive at some assurance that you have included all relevant data and excluded the extraneous? How one might go about solving this complex puzzle is currently being explored

by a number of analysts. It is part of a sizeable effort aimed at understanding the nature of medical decision-making which has been in part stimulated by the need to improve the efficacy and efficiency of high technology diffusion. The attempts which have been made to do so have tended to try three methods or combinations thereof. The first is to develop means for testing the effect of each variable on the outcome while accounting for its interaction with others; the second has been to study the ways in which doctors actually go about reasoning in the clinical setting. The computer has made it possible to do the complicated mathematical calculations necessary for the first approach; while psychological learning theory has helped understand the second. The third path is that of decision analysis which is a complex amalgam of risk and effectiveness calculation, arranged in a "tree" which represents choices, chances and outcomes of available strategies, all of which is negotiable only through the use of complex mathematical calculation.

Is it possible to produce a statistical model which represents the work of decision-making as it occurs in the clinical setting?

The mathematical models usually involve a "linear" pattern of combination in which certain variables are sometimes eliminated, with the retained variables being weighted (with coefficients) and then added to form the multivariable arrangements. The choice of which variables to retain, however, and how to weight and combine them, depends almost exclusively on the reduction of statistical variance in the collected data possessed by the selected mathematical model Although the results are often impressive, none of the statistical

judgments reflects the type of reasoning that occurs in clinical decision.²²

What about, then, a clearer sense of the nature of clinical reasoning making use of learning theory? Patel and others have examined the reasoning structures which are employed in the process of making medical diagnoses.²³ Using inexperienced medical students and trained clinicians as subjects, they have explored the reasoning which each group uses to arrive at its conclusions. What has emerged is a picture which suggests that the more experienced clinicians arrive at their diagnoses much more quickly because they are able to detect patterns in the information which allows them to get a sense of the whole even before they have completed reviewing all of the evidence. This would appear to indicate that a pattern similar to that used in analogous thinking is characteristic of the way in which they proceed. Experienced clinicians seem to cluster data rather than accumulate it in a linear fashion.²⁴ Presumably a similar skill is exercised in other aspects of medical decision-making, but it appears that not much is known about the differences involved in processing information relevant to prognostication.

Decision analysis is an attempt to apply a logically consistent approach to one of the most common problems facing the clinician: how to decide what to do when the consequences of a contemplated action cannot be known with certainty. As applied to an individual patient:

Decision analysis requires three steps, each one a bold attempt to summarize a complex idea. First,

the consequences of each decision option are described systematically by a decision tree. Second, probability is used to quantify the uncertainty inherent in each decision option. Third, each of the possible outcomes of a decision is characterized by a number, which serves as a measure of the patient's preference for that outcome as compared with the other outcomes. These three steps allow one to calculate the average strength of preference for the outcomes of a decision. This value, called the expected value, is the basis for comparing several decision options.²⁵

Does decision analysis offer a superior method for coping with the uncertainty inherent in many medical decisions? The answer is not clear. Many of its defenders acknowledge that a number of serious deficiencies exist in its practice. These include: the simplified models do not always reflect the real problems of the patient; the results are often distorted by the effort to stretch the data available to fit the problem; the utilities used to reflect patient's feelings about the quality of life associated with various outcomes are much more volatile than the present calculations allow. Still the outlook is promising because the method does offer an opportunity for both patient and physician to contribute to the decision in ways which maximize the skill and knowledge of each.²⁶

What this brief analysis has tried to show are reasons why the very process of decision-making is so complex for those who utilize high technology, and the current level of understanding of others who have tried to explore its mysteries. We have attempted to demonstrate why there is so much emphasis upon prognosis as a key element in clinical medicine.

Prognostic decisions are also full of demanding moral

and ethical questions. Prognostic activity involves the forward projection of data regarded as critical determinants for the future course of health and illness in a particular person. High technology is terribly interested in how long and how well a person may live if he undergoes a certain procedure and how soon he will die if he does not. It may not be irrelevant to have an idea of how much each of these possible courses will cost. Those involved in an exercise of this kind (and this includes the patient) must decide what the facts of today will mean when they are as it were, transported into the future to become involved in a dynamic way with other events which can only be anticipated with varying sureness. In addition to the technical challenge involved, this activity makes a number of moral and ethical demands.

1. Predicting the future, as we have seen, has been traditionally reserved to divine action because it was thought to be more than could be claimed for finite creatures. This form of expression is no longer an acceptable way of stating or understanding human limitation. But a valid question as to how much of the future our state of knowledge can allow us to claim still remains.

2. The future is depicted or expressed in terms of percentage of chance or risk but the individual's place on that scale is always non-specific. If the survival rate is 40% after one year, where do I fit remains problematic. But what may be far more crucial is the question as to which of several choices I should accept if the general risk factor is the same. Is

there any possibility of knowing which of these will be better for me?

3. Since the only time which counts in this calculus is that before death, an elaborate trading of time is involved which can be costed. While this could mean that an individual could determine that the "cost" of the possibilities opened up by treatment were worse than death, this does not happen too often in the clinical setting.²⁷ In actuality, the major interest in costing may be that of institutions and government, insofar as they seem to have the overriding responsibility for determining if the projected cost represents an acceptable social value.

4. The paradox lurking in the desire to provide the best treatment for a given disease is that the more personal it becomes, the more likely it is to reduce the range of freedom of choice which is the basis of the principle of autonomy.

Another feature of the construct of the patient is need. In general, persons requiring high technology interventions do not fall into the category of those having a self-limiting illness. They represent supreme dependency upon the ministrations of medicine. This is why we have used the word supplicant to describe their status. They bring out what has been called the imperative to do something. When coupled with two other states -- the relatively high level of uncertainty that accompanies many serious illnesses and the tendency in the face of this ignorance to view high technology as a miracle cure -- the pressure for its wholesale

and indiscriminate application is very great. Frequently we see this condition exhibited in the expression -- "What do we have to lose?"

... the provider may respond to an incomplete or biased perception of the patient's interests. Related to this, the provider's perception of technical efficacy, the relationship between health care and health, may also be incomplete or biased. The "perfect agent" is assumed to be perfectly informed about health care technology and its application to a particular patient, the real provider is not. And the combination of professional training with the perfectly natural desire to "do something good" (or more important, to have done good) for one's patients leads to an overestimate of the efficacy of interventions in general, relative to what can be scientifically substantiated²⁸

Since, as we have seen, the borderline between clinical experimentation and therapy is the intention of the treatment team, considerable room exists for doing what one wishes using the moral justification provided by extreme need.

There is an irony hidden in the results of an ethical overview of the activities of high technology when it comes to evaluating the role of need as the imperative for instigating these interventions. We are pleased by the passage of Good Samaritan laws which establish the legality of the exercise of humanitarian responsibility and query the application of this same concern when it comes to the use of high technology. The fact remains that the search for the "right patient" cannot be abandoned because without this commitment technology becomes an uncontrollable monster.

Further examination of the circumstances suggests that need should be understood as the imperative which arises out of the nature of the medical task as viewed by the doctor and

it would be unwise to expect the profession to adopt another stance. On the other hand, it is equally appropriate to argue that the actions which are impelled by "need," medically defined may be incompatible with other social concerns; and we must look for direction in this matter to the larger setting in which human kind operates.

The immediate stumbling block which this wisdom confronts is one which faces both the individual patient as well as society at large. The doctor and patient are no longer equals facing a common problem. The complexity of medical knowledge has skewed the balance so that the distance between expert and ordinary citizen is difficult if not impossible to bridge.

"... health problems may have a very significant time dimension, developing on a timetable which makes the acquisition of information not merely costly, but impossible."²⁹ Robert Evans has described a number of the characteristics of this asymmetry of information between provider and consumer in health care which go well beyond its economic implications:

... in health care the informational asymmetry extends beyond the process of production or specific characteristics of a good or service, to what its effects will be on the user. How will the care used interact with the patient's condition, whatever that is? The buyer is no longer the best judge of her own interests, but must rely on the seller's advice, which in turn implies that the seller accepts some responsibility for serving the buyer's best interest³⁰

How then are we to view the role played by the patient in determining his fate?

... there remains an important role for patient information and choice of therapy in communication with professional advice, in selecting among available outcomes

and perhaps taking account inter alia of their cost. But the prospects for elimination or significant reduction in informational asymmetry as to the effect of health care on health appear to be very small. Patient education is not a substitute for professional regulation.* Indeed all of what presently passes for "health education," other than the rather banal exhortations to eat a balanced diet and get more exercise and sleep, include recommendations to see one's doctor, dentist or provider more frequently, and comply with their instructions. In any other context this would be easily recognized, not as education, but as marketing of professional services.³¹

In health care systems, such as that in effect in Canada, recognition that there must be an internal response to the existence of asymmetry of information represents a belated but important area for investigation, but discussion of this subject must be postponed to another point in our presentation.

There is still one more matter for our attention, this is the patient's real and projected response to medical intervention. Even here, he does not really remain his own person because the use of drugs in the treatment setting frequently alters important mechanisms of reason such as memory. An example would be the use of valium in the intensive care unit setting. This often results in the patient not remembering that he had given consent to a procedure or been actively consulted in the course of determining his treatment. This is a serious matter because memory is generally regarded as an important component of responsible action. Even under better circumstances, it is difficult but somewhat easier to consider how responsible a person is or may be as a patient. The fact that he may be a

fighter is regarded with approval in the course of calculating his general fitness. Human beings do have an extraordinary ability to make themselves well but it is sometimes difficult to know what value to place upon this power when it may be at least temporarily suspended by the need for high technology rescue.

The uncertainty which has plagued many of the decisions taken in the clinical setting continues to challenge efforts made to improve its efficacy. The demands which efficient use of high technology in the practice of medicine make upon decision-making are goading the profession to consider new ways of dealing with variables in such number that they seem to defy human capacity for their management. The efforts made to bring together hard and soft data by a variety of techniques is a significant step in the upgrading of decision-making to the levels demanded by high technology. But this survey also makes it plausible to ask whether or not certain other safeguards must be in place which offer a perspective of time and value not readily accessible to the individual patient and doctor or health care team. Can the idea of the "right" patient look any different from the perspective of the institution or government? Should it?

... the matrix of decision making is expanded with the introduction of new technologies. Each institutional deliverer of medical care is increasingly faced with a vaster and vaster array of services and facilities to offer. The decisions of which ones to provide are particularly acute, since frequently these technologies are enormously expensive. Because total resources are finite, and because many of these options are expensive,

the cost of foregoing the alternative, which may have resulted in a more impressive impact on health, assumes prominence.³²

How do we relate institutional input to the preceding discussion? By developing the two notions: what questions is it requisite for institutions to ask about the employment of high technology; and how does their organizational structure, both administrative and medical, effect its diffusion? Answering the first should provide an understanding of the goals which HT seeks to fulfill; a response to the second should reveal whether or not it is capable of establishing and reaching these ends. We will follow the concept of needs through the institutional network, seeking to establish what constitutes its role in determining implementation. Having previously developed the idea of the patient in "need" as one of the constructs which is central to the role of physician, it's obvious that one result of this principle in practice has been to relegate to the medical profession the right to determine medical need. This was a highly plausible concept when there was a relationship between an individual patient and a specific doctor. Needs may become a reflection of other perspectives such as those of the hospital and government.

Originally hospitals were established to provide for those members of society who were unable to establish a relationship with a physician for reasons attributable largely to their low social or economic status. In their early form, they were not institutions which were regarded as an ideal

setting for the best medical care so that by the nineteenth century a series of changes took place which made them more attractive to both patients and physicians. They lost their catch-all character, as attempts were made to select more appropriate patients by sending the indigent to almshouses, the hopeless to pest houses, and retaining those who were more likely to survive.³³ A clear distinction began to be made between moralistic and medical objectives.³⁴ The establishment of schools of nursing allowed for introducing professional staff other than doctors.³⁵ The discovery of the bacterial basis of disease and the use of anesthesia provided a more distinct basis for defining their purpose and method of organization.³⁶ It made increasing sense, scientifically and socially, to allow physicians to determine what cases would best be served by hospitalization. The services provided were essentially the same in every institution because very little was known about the kind and distribution of disease throughout a general population; and there was little incentive for doing so because cures for specific diseases were essentially non-existent. As always, the experiences of war provided a vast influx of traumatic injuries which greatly enhanced the role and prestige of the surgeon who was always trying his skill on the next set of the hopelessly maimed and injured.

Within the organization, it became practical and necessary to distinguish between the functions of administration and medical management.³⁷ The former did not have to be

served by a doctor; the latter was exclusively reserved to the medical profession. The financial resources necessary for both were of common interest but responsibility for providing them was reserved to the Board of Governors.

While there was always a consciousness of financial limitation in every hospital setting, this was set mostly in terms of the ability of a patient to pay. In practice, most of these problems could be met by the various schemes of charity that were integral to the formation of the institution itself. However, the possession of ample financial resources did not guarantee a return to health any more than to those who were less affluent.

It was the post World War II technology explosion which made decisions at the patient level much more dependent upon the presence of facilities and equipment selected from among the many options of services that were now open to any hospital. Eventually, at the institutional level, it became imperative to consider which services should remain as new ones appeared, as for example, cardiovascular and thoracic surgery or oncology and nuclear medicine. This necessity for institutional change made questionable the long established division of powers between administration and medical management and when the advent of a national hospital insurance system and medicare brought the hospital budget under control of government agencies, the traditional role of the Board of Governors also was undermined.

A description of a large general hospital as it has

developed in the last twenty years would show the appearance of increasing numbers of sub-specialty medical practices each demonstrating abilities to benefit its highly selective group of patients. These practices make use of and require a much larger capital expenditure than their less sophisticated counterparts of a few years earlier. Overall, in this hospital, there is a geometric increase in the use of laboratory technology, even among those groups which were, more traditional in their practice. Concurrently most institutions would show a budget constraint which would make it impossible to continue the same pattern of usage, let alone allow for growth or change except at the expense of an existing service. Paralleling these developments and even their cause, at least in Canada, was of course the introduction of Medicare. At the same time, increasingly sophisticated information about patterns of health need and treatment outcome came from epidemiologists; and this offered an alternative source of information about needs which had been the exclusive right of doctors to determine.

The resulting situation found few institutions prepared to cope because evaluating competing definitions of medical need was required. Few of the medical or the administrative hierarchies had the training or the authority to make the decisions necessary. Whatever was done was seen as breaking up personal and institutional loyalties, which had generally served the cause of the patients to good end. All too often, the reaction was to temporize in the hope that, with time,

the conditions causing these problems (which were held to be financial) would be temporary. In fact, what the institutions were experiencing was a major shift in the way medicine was practiced. The following points are immediately relevant for our discussion:

1. It is unlikely that any single hospital, including those which are associated with a medical faculty, will be able to offer the range of accustomed services.
2. Planning is a required exercise and will necessitate making use of sociometric and epidemiological techniques for determining medical need, at least to the extent that it will determine the location and distribution of services.
3. It will be difficult to avoid the need to set goals around which planning and evaluation may be instituted. One important area for consideration will be the use of high technology and the processes which will be required to ensure its orderly introduction. This will undoubtedly intrude upon traditional department autonomy, insofar as it may limit who can be sent off for specialized training as well as the freedom to introduce so-called investigative or trial protocols.
4. Many of the issues which are undecided are those for which physicians are not specially qualified to arbitrate, since they involve more general questions of social values and priorities.
5. The composition and role of the Boards of Governors need careful scrutiny. As the only potential way for more general

public representation to the institution, they may be fitting arbitrators in choosing which programmes and services should be implemented. It would not be too much to ask departments and services to discuss the major economic as well as social ethical questions that would accompany the acquisition of or use of a new and experimental technology, be it equipment or technique. That these discussions should be public is obvious.³⁸ The same must happen in terms of individual unit expenses involved for technological innovation at the introductory stage. Cost information is so vital that provision for its availability should be built into every program.

6. Institutions tend to be hamstrung by inadequate planning and evaluation at the level of government and the ministries involved in funding.

7. Planning is not the automatic solution to every problem but without it rational change is impossible.

In Canada, the involvement of both federal and provincial governments in the health care system is mandated by its ultimate fiscal responsibility for the services provided. While questions of jurisdiction may sometimes be raised in order to obfuscate planning and decision-making about health care, this is rarely a decisive factor. Nor can it be said that government involvement syphons off dollars from direct employment for health care by creating a cumbersome and expensive bureaucratic administrative structure. Robert Evans has demonstrated the exceptional efficiency of government participation at this level of costing:

... the cost of operating the insurance program itself, varies greatly across different programs. It is very low in the Canadian public system, while in certain private for-profit plans the load factor may significantly exceed the actual claims paid. Overall, prepayment and administration costs represent 1.5 percent of health care costs in Canada, and 2.5 percent of the hospital and medical care costs which form most of the insurance load. (Canada, Health and Welfare Canada, 1979). Corresponding American proportions are 5.2 percent and 9.0 percent, but these include public Medicare and Medicaid programs, as well as self-payment. Private sector prepayment and administration costs are 13.4 percent of total private sector health care reimbursement (net out-of-pocket and public sector payment), and 19.1 percent of private hospital and medical care reimbursement (Gibson et al., 1983). Load factors for private insurance plans in Ontario are in the 10-20 percent range (Ontario, Ministry of Treasury and Economics, 1981).³⁹

Obviously by controlling the purse strings, government is in the position to be able to influence decisions as to what kinds of medical needs fall under the purview of the system. The methods for actually controlling practice and thus defining need include:

1. The global budget system for hospital running expenses which is based upon a floor level reflective of the services offered at the date of calculation.
2. A separate capital budget which is subject to special scrutiny. New programs having capital requirements are controlled in this way.
3. The authority to regionalize services whenever it is deemed expedient to do so.
4. The ability to shift budget priorities from one part of the system to another, e.g. primary care, chronic care.
5. Standards of efficacy and efficiency for individual

practices or technologies to be set.

6. Possessing a data base upon which various parts of the system may be evaluated or costs-benefit analyses performed.
7. The command of important powers of persuasion and moral authority which can influence social attitudes and values.
8. Ultimate responsibility for the allocation of resources within the area of its jurisdiction. This would include the mandate to consider the needs of future generations as they weigh against those of the present.
9. The requirement to seek an elected mandate at regular intervals.

It is not easy to determine what should be taken as representative of governments at work in the area of high technology medical innovations. We have decided to accept the Report of the Working Group on Vital Organ Transplant Centres to the Deputy Ministers of Health,⁴⁰ as our exemplary document. It was written on the directive of the Conference of Deputy Ministers of Health which brings together the chief civil servants for health at the provincial level to discuss on a regular basis items of common concern. The terms of reference were:

To advise the Conference of Deputy Ministers of Health on matters related to vital organ transplantation for the purpose of formulating national and/or provincial policies and planning programs.

Specifically, the committee should advise regarding:

- a) the financial implications of vital-organ transplant centres
- b) the potential volume of transplant procedures in Canada and regionally

- c) the standards and guidelines for the establishment of transplant centres
- d) the standards and guidelines for the establishment of organ preservation services
- e) the number and location of vital organ transplant centres*
- f) research, teaching and development and information system requirements
- g) legislative implications, if any, of developing vital organ transplant centres, particularly in relation to organ retrieval, storage and disposal

*This is a slight emendation from the original terms. In particular, ... the word "required" deleted from the end of (e). This latter change was made to recognize individual provincial jurisdiction on this matter.⁴¹

The impetus for this mandate and the results it produced was a paper from Manitoba put forward at the Conference of the Provincial-Territorial Ministers of Health which was held in Calgary on September 5-6, 1984. Entitled "Regionalization of Very Special Services -- Tissue Transplantation," its recommendations -- that interprovincial centres should be created each to specialize in one service area and that an interprovincial working group should be created to study the question -- were accepted. The actual working group and its terms of reference were created by a meeting of Deputy Ministers held in early November of the same year. It gave those involved ten months (until September 1985) to produce a report.⁴² The result is quite an exceptional document. Obviously, those involved in its making had no time to be original and were therefore heavily dependent upon major research efforts such as the British and American studies on Heart Transplantation which appeared shortly before this committee began its work. It is remarkably free from obtuse and ambiguous language and presents a comprehensive summary

of the current scene in transplantation. A better example of its type would be hard to imagine.

The Working Group endorsed also the notion that studies of this kind are instruments for public education:

(it) strongly recommends that the Report be circulated to such interested groups* for comment in order that the widest consensus possible be obtained. In this way, it is more likely that future problems will be avoided.⁴³

A salutary observation on the outcome of this intention would note that there is little evidence that this wish has been realized. Certainly there are few references to its existence in later literature.

What do its contents and recommendations contribute to the understanding of decision-making about the use of high technology medicine which we are trying to develop?

1. We can acquire an idea of what could be considered to be the role of government in this process. Under the heading of "General issues" the committee found it relevant to include:

Ethics and Scarce Resources -- Universality and Accessibility; Cost and Funding Problems; Transplantation compared to Other Treatment Modalities; The Pace of Change; and Volume Limits Underlying all of the analysis and discussion are two, often conflicting but absolute considerations -- quality of care and costs of care. Organ transplants are a part of current and future medical practice -- they will not disappear, nor does the Working Group believe it is desirable or possible for them to be stopped.* The issues, then, are how well can the service be provided, looking at quality for the individual patient, and for the population's health care requirements; and at what cost, (given the need for acceptable standards) looking at alternative arrangements? The issue of timing of the planned development is also relevant In most other circumstances not only were cost and quality considerations usually opposed, but, also, the costs and quality for individual patients versus those

for populations and Health Departments were often different. Therefore, for most conclusions and recommendations, there is a legitimate case for arguing alternative solutions, dependent on the weight given to quality and cost considerations and to individual patients and health care system points of view. The Working Group's proposals try to balance these factors in the light of current knowledge and the present socioeconomic circumstances.⁴⁴

A more detailed summary and analysis of its recommendations is now in order.

It seemed to appreciate the argument that many issues of policy are inescapably connected to ethical responsibility and that this was particularly true for matters concerning equality of access and allocation of health care resources.⁴⁵ It accepted the possibility of there being a point at which the limits of services covered by government insurance services could be reached; but, on the other hand, it could not sustain a refusal to insure technologies which were viewed by the public as "life-saving." This seemed to invite the conclusion:

It is recommended that the availability of resources should determine when the different transplant services can be provided in each province or region, leaving judgment on individual cases to be determined by the circumstances -- i.e. make no policy statement except a very general one covering universality and accessibility, bearing in mind financial resources.

This may be seen by some critics as covert rationing, or as an abdication of responsibility by government. It should be remembered that such decisions are already being made. Current demand exceeds supply for most organ transplants. In the case of kidneys, there is the alternative of renal dialysis. There is no such fall back in the case of hearts and livers. Consequently, patients are dying because choices must be made between possible recipients. The viewpoint of medical practitioners also affects accessibility as referral rates to

transplant centres will vary. Transportation and distance are also likely to alter the demand for treatment.⁴⁶

As we see it there is some substance to the criticism offered about this recommendation. The issue centers upon what levels of responsibility are appropriate for which decisions. There is no question about the fact that determinations have to be made between possible recipients, or that individual physicians vary in the extent to which they refer patients for transplantation. There does not seem to be any disagreement as to the appropriateness for those decisions to be taken at a non-governmental level. On the other hand, it does not seem reasonable for allocation matters to be considered at any level other than government. We have seen when this decision is left to the local institution, the effect is to create chaos and inefficiency. Two things can be said about the conditions which have led to this conclusion: one, it reflects the fact that attempts are being made to regulate transplantation after it is an accepted practice, rather than to produce a means for its orderly introduction; and two, allocation questions are politically controversial and it is to the advantage of governments which must seek regular popular mandates to shift the responsibility for their implementation. But there is an even more important matter which is brought to light by this Report. This is the state of transplant procedures not yet in common practice.

Sufficient experience for evaluating new forms of transplantation now exists. It would be possible to designate

some of the procedures mentioned in this Report as experimental, e.g. heart and lung and pancreas. Indeed, it suggested as much, but no particular significance is attached to this distinction. Would this not be the opportunity to set a precedent by designating one or two centres to undertake clinical trials for a five-year period and charge them with providing for their appropriate evaluation? This would mean that the data necessary to calculate the effect upon resource allocation, if they were fully implemented, would be relatively easy to obtain. No high technology should be allowed to come "on-line" without this kind of consideration.

A special concern needs to be raised about the transplantation of young children and babies. The ethical dilemmas are particularly thorny.

a) Their need is particularly acute. Most of these young patients will die more or less immediately if they are not transplanted.

b) The need to have special protection given to children who may be considered for medical experimentation is universally acknowledged. The benefits of any proposed trial must be to the child himself and not to general medical knowledge if any risk is involved. Presumably, death is the immediate prospect if transplantation is not attempted; but in the case of a child, is it necessary to require something more? This leads to the question as to how much knowledge about Transplantation over the long term should be mandatory before it is tried on children.

- c) Since a transplant turns an acutely ill person into a chronically ill patient, there are clearly some trade-offs for postponing death. In the case of an adult, it is the possibility for five or more years of life of reasonable normalcy. The cost is considerable, both monetarily and biologically with the dependence upon immunosuppression and its side effects. Of what value is this experience when it is transferred to a one-day-old infant?
- d) The closest comparison which comes to mind is that provided by insulin dependent children. Originally, at least, it was not possible to tell what would happen to them in the long run if they were insulin treated diabetics. The prospect seemed a better alternative than acquiescing to their continual suffering and eventual death. On the other hand, even for that time, the treatment was not that expensive and did not involve serious questions of resource allocation.
- e) There is no question that giving a baby a new heart does commit that child to participation in a life-long clinical experiment, because the long term effects of transplantation are of considerable interest for someone who has to live longer than anyone ever has with a transplant just to reach the age of 18! This condition alone warrants Lewis Thomas's description of a "half way technology" to describe the transplantation of children.
- f) The high survival rate of cardiac and liver transplants in children points out how possibly misleading this measure of success may be and the need to make the public more aware of

the uncertainties present in the present standards of evaluation.

2. We are somewhat reluctant therefore to endorse the description of ethical issues with which The Report begins Appendix C:

Thirty years ago, ethical considerations concerning transplantation focused on the experimental nature of the procedures. With ever-improving graft survival, ethical questions now translate to policy issues concerning:

- . the allocation of health resources to transplantation compared to allocation to other health services
- . equitable access to transplantation
- . who should be transplanted.⁴⁷

The operative word here is experimental and how the problems present in transplantation are to be understood in the face of greatly improved survival in some procedures. It is clearly a mistake to lump all transplant procedures together, since each one represents somewhat varying problems in terms of the relative complexities of the surgical techniques involved; the idiosyncracies of the immunosuppression required for different organs; the nature of the end-stage disease process to which a particular transplant responds as well as the problems peculiar to the number and condition of donor organs available. It would seem more appropriate to suggest that, in addition to the ethical issues which were present in the early stages of transplantation, a number of others has emerged relative to the success of this high technology.

We have noted that the report has selected three ethical issues as newly relevant. The first is resource

allocation and from its point of view the basis for resource allocation decisions requires justification in terms such as:

- . the relative costs and benefits of the service
- . the value of these benefits compared to other benefits which are foregone by allocating resources to this service
- . congruence with goals of the health care system.⁴⁸

The dependence upon cost/benefit findings is, as we have seen, somewhat controversial because it is not a standard which has been uniformly applied in evaluating health care procedures.

The way out taken by the committee is to argue that the basis for comparison should be the costs of transplantation relative to those which are required for end-stage treatment of patients with the same disease. In keeping with this line of reason the Report concludes:

While the ethical question of the value of dollar expenditures for transplantation compared to dollar expenditures for other services cannot be fully addressed, one can point to the considerable benefits associated with organ transplantation. Nevertheless, the scarcity of resources and the public demands for other services will make it incumbent on the transplant program to demonstrate to the public that the benefits associated with the transplant program are sufficiently great to justify this expenditure. Evaluative research should be encouraged to be part of transplant programs so that the benefits of the program can be scientifically demonstrated to the public.⁴⁹

The call for evaluation is welcome but it begs the crucial ethical question: how benefits of various programs are to be compared and whether or not scientific demonstration can be the determinative factor in this process.

In another discussion of the ethical issues we have just examined, the Report asks:

In considering the allocation of dollars and of donor organs a number of ethical issues present themselves: should scarce health dollars and scarce donor organs be used for recipients where minimal benefits may accrue? But what are minimal benefits -- increased life expectancy of only a month, a year, two years? Should scarce resources be invested in individuals whose life expectancy is extended but whose potential for rehabilitation and contribution to society is limited? If there are to be selection criteria, to what extent should medical, psychological, socio-economic factors be part of the selection process?⁵⁰

At this point the Working Group apparently came to the conclusion it was time to turn tail and run: deciding apparently that it was sufficient to leave as a parting offering a summary of the way in which one may approach the "rationing" of scarce medical resources according to either utilitarian or egalitarian principles. Before we consider what this summary may show, we would raise a question as to the appropriateness of the term rationing to describe what is being advocated.⁵¹ In general, rationing works because there is a more or less generally agreed upon basis for dividing what is to be distributed. It is precisely this kind of information which is lacking or only partially available when we come to most allocation decisions related to health care. The most obvious example is the difference between health status and health care.⁵² What the Working Group in fact is omitting is a consideration of what process might be devised to enable decisions to be made of the kind which are required for determining health care availability. Although the list of utilitarian and egalitarian principles is lengthy, it is important for our discussion to include it at this

point. This list reinforces our contention that it is absence of process rather than principles which lies at the basis of the current dilemma.

Utilitarian Principles:

U-1 The principles of medical success. Priority given to those for whom treatment had the highest probability of success.

U-2 The principle of immediate usefulness. Priority given to the most useful under the immediate circumstances. (Those who could be of most service to the larger group).

U-3 The principle of conservation. Priority given to those who require proportionately smaller amounts of resources.

U-4 The principle of parental role. Priority given to those who have the largest responsibilities to dependents.

U-5 The principle of general social value. Priority given to those believed to have the greatest general social worth.

Egalitarian Principles:

E-1 The principle of saving no one. Priority given to no one because none would be saved if not all can be saved.

E-2 The principle of medical neediness. Priority given to the medically neediest.

E-3 The principle of general neediness. Priority given to the most helpless or generally neediest.

E-4 The principle of queuing. Priority given to those who arrive first.

E-5 The principle of random selection. Priority given to those selected by "chance."⁵³

Another writer listed four major approaches to rationing resources as follows:

1. The "market approach" which provides an organ to everyone who can raise funding (privately or otherwise). It is not an approach which focuses on equity or fairness, just ability to raise adequate financing.

2. The "committee selection approach" is used where the

establishment of specific selection criteria is deemed unworkable. Without standard criteria, the selection process ends up showing preferences to certain individuals, and undermines, as does the market approach, notions of equality.

3. The "lottery approach" focuses totally on a crude interpretation of equality and as a result makes no distinctions on issues such as potential survival and quality of life.

(This is the same as Winslow's principle of random selection.)

4. The "customary approach" has been to avoid explicit recognition that choices have been made not to save lives. For example, until recently, in Great Britain there was a general understanding among practitioners that dialysis was not to be provided to individuals over the age of fifty-five. When this practice became public in 1984 along with the disclosure that there were 1500-3000 "unnecessary" deaths each year, there was pressure to increase the National Health Services budget to expand dialysis services.⁵⁴

The Report observed that according to these standards there were at the present time several of these approaches in use in Canada, either singularly or in combination. It singled out, medical success, medical neediness and queuing as obvious and noted that the customary approach probably had some advocates as well.⁵⁵ It raised the spectre of Section 15 of the Canadian Charter of Rights which prohibits discrimination on the basis of age, sex, mental or physical status, etc., and offered the comment that for this reason protocols based on medical criteria will become extremely

necessary. It suggested further, that age could not be a factor for denying access to transplantation unless prognosis were poor. Once again, the point has to be made as to how definitive legal strictures can be for enabling us to use high technology to maximum social benefit. Should there be any limits on the amount of time a person should be able to buy?

After having given some space to a summary of the ethical principles that have found acceptance in the history of our society, one wonders how they might apply to government recommendations as a matter of considerable importance for our future society.

For government, the ethical issues translate to whether there should be a more active role in monitoring the location and number of transplant centres, cost differences between centres, and distribution of donor organs. The question of whom to transplant remains a medical decision based on prognosis for survival and rehabilitation. These decisions will be subject to ongoing revision as medical technology advances and as capacity is made available through the funding of hospital and physician services.⁵⁶

A final observation seems in order. What has emerged in our discussion of decision-making as it affects the diffusion of high technology, has been the notion that the medical profession feels it has neither the responsibility nor the power to decide how the system should proceed with the adoption of HT. Many of the most frustrating aspects of providing health care today arise from the fact that the crucial decisions must be based upon social values and goals, traditionally forthcoming from the government, as expressive of the

political will. Apparently, our current political practices are incapable of providing guidance on matters such as the goals of our health care system and new ways may have to be sought for determining the commonweal.

Footnotes to Chapter V

¹Alvah Feinstein, "The Intellectual Crisis in Clinical Science: Medalled Models and Muddled Mettle," Perspectives in Biology and Medicine, Vol. 30, No. 2, Winter 1987, p. 228.

²During that time there were 45 meetings in which patients were evaluated and a decision reached as to their status. In addition, the Team used this time to develop the criteria it used in making decisions. On the work of a participant observer in these circumstances, see C. Bosk, "The Fieldworker as Watcher and Witness," Hastings Center Report, Vol. 15, June 1985, pp. 10-14.

³Throughout this portion of our work the singular pronoun "he" will be employed as is appropriate. This is not to be sexist, but to try to maintain some simplicity of style. In point of fact whenever we are referring to heart transplantation this use is factually on the mark since more than 90% of the patients are male.

⁴Eric Cassell, The Healer's Art (Philadelphia: Lippincott, 1976), p. 56.

⁵Referring to a patient recently given an artificial heart, his West German surgeon was quoted: "We have not told the patient that his own heart was taken out and replaced with an artificial heart because we wanted to prevent him from being disturbed." The New York Times, March 9, 1985.

⁶Cf. C. Whitbeck, "Why Pay Attention to Paternalism in Medical Ethics?" Review of Who Shall Decide? Paternalism in Health Care by James F. Childress (New York: Oxford University Press, 1982) in Journal of Health Politics, Policy and Law, Vol. 10, No. 1, Spring 1985, p. 183.

⁷Canterbury vs. Spence as quoted in T. Beauchamp and J. Childress, Principles of Biomedical Ethics, 2nd ed. (New York: Oxford University Press, 1983), p. 293.

⁸Cf. Claire Bernstein, "Court Confronts M.D.'s With Tough Dilemma," The Gazette, Montreal, August 5, 1987, p. C-2.

⁹T. L. Beauchamp and J. C. Childress, Principles of Biomedical Ethics, p. 78.

¹⁰Cf. E. Cassell, "Ideas in Conflict," p. 27.

¹¹A. Feinstein, "An additional Basic Science for Clinical Measure; IV. The Development of Clinimetrics," Annals of Internal Medicine, Vol. 99, No. 6, December 1983, p. 845.

¹²Ibid., p. 843.

¹³E.G. the calculation of Pulmonary artery resistance and psychosocial information about the patient's familial support network.

¹⁴Cf. Chapter I, note 24; but see C. M. Herrick et al., "Combined Heart Failure Transplant Program: Advantages in Assessing Medical Compliance," Heart Transplantation, Vol. 6, 1987, pp. 141-146.

¹⁵A. Feinstein, "An Additional Basic Science for Clinical Medicine: IV." p. 848.

¹⁶A. Feinstein, "The Intellectual Crisis in Medical Science," p. 222.

¹⁷In the flow-sheet used at RVH there is write-in space to record information which is soft, but no established and systematic practice of doing so.

¹⁸A. Feinstein, "The Intellectual Crisis in Medical Studies," p. 219.

¹⁹D. W. Evans, "Cardiac Transplantation." (Correspondence). British Heart Journal, Vol. 55, No. 4, 1985, p. 472.

²⁰A. Feinstein, "An Additional Basic Science for Clinical Medicine: IV," p. 848.

²¹A. Feinstein, "The Intellectual Crisis in Clinical Science," p. 224.

²²Ibid., pp. 224-225.

²³V. Patel et al., "Predictive Versus Diagnostic Reasoning in the Application of Medical Knowledge," read at Cognitive Science Society Meeting, 1985; G. J. Groen and V. L. Patel, "Medical Problem-solving: Some Questionable Assumptions," Medical Education, Vol. 19, 1985, pp. 95-100; V. L. Patel, et al., "Biomedical Knowledge and Clinical Reasoning: Role of Situation Models," in D. Evans and V. Patel (eds.), Cognitive Science in Medicine, forthcoming;

V. L. Patel et al., "Case Comprehension Approach to Medical Decision Making," presented at symposium, "Cognitive Processes in Medical Decision Making: A Critical Appraisal," Chicago, April 1985; V. L. Patel, et al., "Differences Between Medical Students and Doctors in Memory for Clinical Cases," Medical Education, Vol. 20, 1986, pp. 3-9.

²⁴ A. Feinstein, "The Intellectual Crisis in Clinical Science," p. 225.

²⁵ H. C. Sox, Jr., "Decision Analysis: A Basic Clinical Skill?", New England Journal of Medicine, Vol. 316, No. 5, January 29, 1987.

²⁶ S. G. Pauker and J. P. Kassirer, "Decision Analysis," New England Journal of Medicine, Vol. 316, No. 5, January 29, 1987, p. 257; also J. P. Kassirer, A. J. Moskowitz, J. Lau, and S. G. Pauker, "Decision Analysis: A Progress Report," Annals of Internal Medicine, Vol. 106, No. 2, February 1987, pp. 275-291, esp. p. 285.

²⁷ This is one of the difficulties of using utilities to construct treatment plans before the fact.

²⁸ R. G. Evans, Strained Mercy, p. 77.

²⁹ Ibid., p. 70.

³⁰ Ibid., pp. 72-73.

³¹ Ibid., p. 74. *Evans notes here, "The strong interest in information and self-care among certain groups of females in particular appears to be a response to predominately male providers who are alleged to use expertise in the technical domain to try to impose their own preferences in the outcome domain, i.e. to enforce by control of information and access to other facilities or commodities, choices which lead to health outcomes providers think patients ought to want, whether they do or not."

³² L. R. Tancredi and A. J. Barsky, "Technology and Health Care Decision Making," p. 847.

³³ Paul Starr, The Social Transformation of American Medicine (New York: Basic Books, 1984), p. 151.

³⁴ Ibid., p. 158.

35 Ibid., p. 155.

36 Ibid., p. 156.

37 Ibid., p. 161.

38 L. R. Tancredi and A. J. Barsky, "Technology and Health Care Decision Making," p. 854.

39 R. G. Evans, Strained Mercy, p. 38.

40 Working Group on Vital Organ Transplant Centres, The Report to the Deputy Ministers of Health, Ottawa, September 1985.

41 Ibid., Appendix A, p. 101.

42 Ibid., p. 1.

43 Ibid., p. 3. *Professional bodies such as the Canadian Transplantation Society or voluntary groups such as the Canadian Liver Foundation, etc. # emphasis in the original.

44 Ibid., pp. 4-5; *emphasis mine.

45 Ibid., p. 5.

46 Ibid., p. 6.

47 Ibid., p. 107.

48 Ibid., p. 107.

49 Ibid., p. 109.

50 Ibid., p. 111.

51 A. Caplan, "The High Cost of Technological Development: A Caveat for Policymakers," in A. S. Allen (ed.), New Options, New Dilemmas, p. 91.

52 R. G. Evans, Strained Mercy, p. 4.

⁵³Working Group on Vital Organ Transplant Centres Report pp. 111-112, from G. R. Winslow, Triage and Justice (Los Angeles: University of California Press, 1982), pp. 105-106.

⁵⁴Ibid., p. 113 quoted from United States House of Representatives. "Organ Transplants," Hearings Before the Sub-Committee on Investigations and Oversight of the Committee on Science and Technology, 98th Congress, First Session, April 13, 14, 1983, pp. 3333-3340.

⁵⁵Ibid., p. 113.

⁵⁶Ibid., p. 114.

CHAPTER VI

GIVING TIME -- THE DONATION OF HUMAN ORGANS

What makes transplantation such a special activity is often unnoticed. This is the startling discovery that under certain conditions the human body could be a source of spare parts, and that hearts, kidneys and lungs, for example, could be replaced in much the same fashion that a defective carburetor is changed in an automobile engine. Recent attention has tended to focus upon the need for increased organ donation and obscured the technical, scientific and ethical developments which have made us, as a society, somewhat comfortable with the practice of salvaging organs from dead human beings. We believe it is important to remind ourselves of how much this practice "costs" and therefore why it is not surprising when our sensitivities are challenged every time a new technical opportunity for using human organs arises such as with the case of anencephalic babies or aborted fetuses.

The historical setting... Vital organ transplantation became clinically possible in the late 1960's when kidney transplantation passed from the experimental stage to being a recognized therapy for the treatment of end-stage renal disease. Initial success had been based upon the availability

of compatible donors who were living near-relatives of the recipients. The potential of cadaveric donors was quickly explored when it became obvious that close living relatives of possible recipients could not meet the demand for compatible organs. Their use would be possible only if immunosuppressive therapy became sufficiently effective so that the genetic differences between unrelated donors and recipients could be overcome without the rejection of the transplanted kidney by the new host. The immunological knowledge which made this step possible was an impressive example of the important interplay between basic research and clinical progress in medicine. Basically, it noted that not only was ABO blood group compatibility essential between the parties, but there existed a human leukocyte antigen system (HLA) of histocompatibility antigens which greatly influenced immunologic compatibility. The knowledge which emerged showed that this was a highly polymorphic system, determined by a major histocompatibility complex on the shortest arm of the sixth human chromosome. The functionality of this complex was the work of a large number of alleles (the alternative forms of a gene at the same site in a chromosome) at the A, B, C, and D loci which segregate according to the classical laws of Mendelian inheritance. Their presence explains why it is possible to have a rational selection of donors within families in which the genetic determinants of antigens are limited, and the great difficulty in achieving compatibility or perfect matching between an unrelated donor and recipient.

In addition to the development of an immunosuppressive therapy which could overcome the effects of the genetic differences which were inescapable between non-related subjects, another matter needed settling for cadaveric organs to be available. This was a legal and moral question which was resolved by a newly developed medical technique for determining the death of patients on the basis of neurological evidence or so called "brain death" criteria. This made it possible to distinguish between a person as a patient, with all of the moral-legal protection thus acquired, and a donor, an individual who was legally dead but who continued to have, for a time, viable vital organs.

Subsequent developments in organ transplantation These have made it possible for the successful implantation of hearts, lungs and livers and have made dependence upon cadaveric organs essential for the continuation of transplant procedures and even have made many experts sceptical of using living donors when this still is technically and legally possible.² The high profile of transplantation and the trumpeting of its successes have made the general public highly aware of its existence and generally positive in its acceptance of this medical technology.³ However, actual donation of organs has been at a level considerably below either the approval rate of transplantation,⁴ or the indicated willingness of individuals surveyed to give their organs or those of a family member.⁵

Another view of these events and issues

Transplantation starts with the knowledge that one human body can be a source of spare parts for another; this in turn produces questions as to the circumstances under which exchange of vital organs should be permissible, medically, morally and legally; which raises the matter of the kind of knowledge required for this to be a rational process; and that results in the necessity for determining the type and form of controls to be placed on their use.

In the accounts recalling the early efforts at transplantation, little has been revealed about how those involved went about acquiring donors. In the case of kidneys, they were initially living near-relatives who had to be convinced of the potential good and prepared for the possible risk that donating a kidney involved. The reading presented by Fox and Swazey puts the matter in these words:

The donor who offers a part of his body for transplantation is making an inestimably precious gift. The acutely ill patient who receives the organ accepts a priceless gift. The giving and receiving of a gift of enormous value, we believe, is the most significant meaning of human organ transplantation. This extraordinary gift ... takes place within a complex network of personal relationships Within the network of these relations, a complex exchange occurs through which considerably more than the organ itself is transferred ... organ transplantation takes place under circumstances that impose constraints upon the persons involved, and within an interactive framework that structures the situation for them in ways that limit and bind as well as open and free. The freedom to give or to receive an organ is neither absolute nor random. These freedoms are mediated and governed by the norms of gift exchange, on the one hand, and by an at once biological, psychological and sociobiological screening process that we refer to as "gatekeeping" on the other.

Others such as Ramsey have called attention to the

rooting of organ donation in the language of the gift and argued that this base delineates the moral and ethical structures which governs its use and regulation.⁷ It is, however, not very obvious how to move from an understanding of organ exchange as a gift relationship to its institutionalization, particularly when the goal of this effort is making parts of dead persons available as a common or ordinary event. In the end this is the only way to meet the demand for vital organs. One element in the success story that marks transplantation, at least in North America, has been its ability to capture or possibly symbolize a spirit of altruism in which all of society can take pride. But the closing sentences of The Courage to Fail have sensed how limited this emotion can be as a means for coping with the larger impact of high technology:

The theme of the gift, of freedom and obligation in the gift, of generosity and self interest in giving reappear in our society like the resurrection of a dominant motif long forgotten. Marcel Mauss wrote (Mauss, 1954, p. 66). Organ transplantation is one recent development that has again brought such issues of gift exchange and social solidarity prominently into view. Transplantation and hemodialysis also center on problems of uncertainty, meaning, life and death, allocation and scarcity, and intervention in the human condition. This is where the ultimate significance of these therapeutic innovations ... is to be found.⁸

In practice ... the emphasis upon the life-giving gift was continued when cadaveric organs became the principal source of supply of vital organs, but a number of challenging issues claimed the attention of those who wished to proceed with transplantation. The most pressing was the legal one of

avoiding being open to the charge of murder while at the same time ensuring that the organs in which they were interested retained their viability until they could be removed.

Unfortunately, there does not appear to be any record of what those who pioneered harvesting of organs from the newly dead actually thought and talked about as they developed the protocols which governed their action. The donors in Christian Barnard's first heart transplant are not just anonymous; they appear to be almost accidental in their presence. But, the publication in 1968 of the report by the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death entitled, "A Definition of Irreversible Coma," was seized upon by those engaged in transplantation as of incalculable assistance in coping with the dilemma as to when a patient, undergoing medical treatments which substituted for vital body functions, ceased to be a patient and became a dead body with vital organ function intact. (It is important to note that the reason for the Harvard report was not to assist transplant surgeons but to deal with the moral and legal problems presented by the development of new life support technology.) Obviously, such persons were not dead in the more common use of the term and to introduce a brain qualification for determining the absence of life was a concept difficult to comprehend, having no commonly accepted form of measurement until the Harvard criteria came along. The use of the cadaveric donor did something else as well; it altered the nature of the gift relationship which had been

submerged in the dynamics of the family relationship and substituted for it the more impersonal category of altruism. This change enabled organ donation to emerge as an act which could be quite easily brought under the wing of the vast institutional structures for doing good, which were a major part of North American culture. The organization of the first two renal banks for procuring, preserving and distributing kidneys and eventually other organs occurred almost simultaneously in Boston and Los Angeles, in 1968. Since that time, these organizations have increased in number and sophistication with their scope becoming enlarged from a regional to a national scale. Although other bases for acquiring organs have been suggested, such as the market approach of buying and selling them,⁹ such efforts to shift from the principle of donation as an expression of altruism have been successfully resisted, and this resolve has been supported by the profession,¹⁰ as well as patient groups and various levels of government.

Organizing altruism This is rarely a simple task and organ donation is no exception. Before approaching the issues which have emerged out of the need to increase the supply of vital organs, a brief detour is in order to examine the attitudes and emotions which underlie the human response to death and the dead. In North America these find expression in several forms:

1. The dead are to be honored by respectful treatment of their bodies.

2. Those who mourn deserve special consideration and this has meant allowing them to view the deceased and to be able to have custody of the body without undue delay.

3. The change in status which death represents is often marked by a formal rite of passage, such as the funeral or memorial service.

4. Increasingly, public attitudes towards death have been influenced by funeral directors who have replaced more traditional sources of expertise in this matter, viz. the clergy.

5. Nonetheless, religious practices and taboos are, particularly operative in the event of death.

Together these attitudes and practices have constituted a tradition which has helped members of this society to cope with the personal and communitarian threat which death represents. To the extent that this is possible, they allow individuals and groups to feel that they know what to do on this occasion. The advent of the dead person who is an organ donor breaks down, in a number of ways, these carefully built up defenses by which death has been made personally and collectively manageable. The high technology fix which transplantation represents has placed a new burden on hospital personnel as it must assume an intermediary role between the dead and the living which dislocates the assumptions held about who is alive and who is not. At the same time it offers increased anguish as well as opportunity to those who mourn. The major characteristics of this state are:

1. Donors represent a new "class" of the dead and we have no tradition for dealing with what they represent.¹¹
2. It is difficult to distinguish their appearance from that of other patients in the ICU or Operating Room. "Brain Death" is not an easy concept to picture and violates a long medical tradition for detecting the presence of "life."¹²
3. Reflexively, the instinct is to treat them as persons and to view the surgical procedures necessary to remove organs as invasive and a violation of their being.
4. The underlying tragedy of the death is very obvious because donors are children or previously healthy and most often young persons whose future has been unexpectedly brought to a close. It is some comfort to know that this tragedy can bring life to someone who would otherwise die. In perspective, the "gift of life" aspect of donation is only a partial substitute for the loss which has occurred, however much it may enable those involved to salvage some purpose for an untimely death.

The dynamics of death, which we have just outlined, have intruded upon the discussion concerning strategies to increase the donation of organs. They have led to some conflict between the gift relationship approach to providing organs and one based upon altruism and the practical and logistic requirements for developing dependable, regular "donation" on a large scale.¹³ These factors have been neglected in the discussion about tactics for increasing the supply of organs because it has conceived of the problems as an

implicit result of the "voluntarism" involved. This we believe is an illustration of almost exclusive dependence upon political philosophy and law as a source for understanding recent controversies in the regulation of medical practice.

In the course of examining the developments which have made cadaveric organs available for transplantation from its beginnings in the odd hospital to a large scale regional and national network, we will try to account for the persistence of the notion of "the gift" as both a norm for restricting the methods employed to increase the availability of vital organs as well as a tool of marketing, with the same goal in mind. The results of this effort include: practices and protocols intended to protect the interests of the patient who may be a prospective donor; protocols which try to maximize the vital state of body organs in the period of transition from patient to donor; techniques designed to discover the maximum number of potential donors; marketing and counselling methods which try to obtain permission to retrieve the organs of potential donors; efforts to sensitize the general public to the value of organ donation.

1. As we have seen organ donors are persons who die under special circumstances which make it possible to suspend temporarily the effect of death on some of their vital organs. It is high technology treatment, viz. the use of life support systems, which has, as an incidental result, created usable organs following death. What initiates this treatment is the

attempt to save the life of a patient. What causes discontinuation of the same procedures is death or the ineffectiveness of the treatment and not the need for some part of his body for transplantation. It is morally and legally necessary to understand the interests of the persons involved in these conditions, and to provide for the protection of each. This means that no one connected with the future use of someone's body organs can have any decision-making power over the care of someone who is potentially a donor. This reservation covers both treatment and the declaration of death. As it happens in real life, honoring this commitment often involves analyzing practices in order to see if they honor the spirit of this crucial distinction:

a) Large doses of dopamine are often indicated for maintaining adequate cardiac output when there is severe brain damage.

This is necessary to keep fluid accumulation at a minimum in the brain. Hypovolemia, in conjunction with large dosage of drugs such as dopamine over extended periods of time, results in a heart which is unfit for transplantation. It makes sense to use dopamine only to the point at which it will improve a person's prognosis if this knowledge is available, but if it is not, is this restriction incompatible with the patient's best interest? Does it violate the separation of interests to consult the transplant team on this matter?

b) There are some patients on life support who are certain to die but will probably do so via a near persistent vegetative state which could last for some time, i.e. they will never

actually have a "dead" brain stem. It is permissible to discontinue life support for these persons because nothing further can be done to restore them to a conscious state, but their death will come through cessation of heart beat and breathing and will mean that these organs cannot be used for transplantation. Would it be permissible to test these persons at intervals for the presence of spontaneous heart beat and respiration; and, if they are absent, declare them dead and resume life support in order to use their organs? This is, in effect, the practice employed in order to salvage the organs of anencephalic babies.

At the present time, there is little opposition to the current practices which try to maintain real distinctions between the desire to keep alive the potential donor and the needy recipient. The requirement that different physicians who have no conflict of interest be the advocates of each party is accepted in both theory and practice. But with the potential for one person to be a multi-organ donor and save 5 or 6 lives, the conflicts of the kind we have just noted, even if they are rare are of great importance for all concerned. Observing the principle that organs should come from persons who are legally dead, and not merely useless as functional human beings, has so far been possible, but it may be increasingly difficult to maintain this distinction in the face of the need for vital organs and more sophisticated medical science. The time, i.e. life, which is generated by transplantation is conceptually difficult to evaluate,

particularly when it is viewed from the perspective of the gift. It is acceptable to lay down one's life for one's country (community). Is it any different to give one's vital organs away when it is clear life has no future for you?

2. The creation of a new class of persons called organ donors has made it necessary to construct rules and practices to govern its care. Since there are always more demands for organs than can currently be met there is intense pressure to salvage all usable organs from each potential donor. The complexities involved here are not only medical, they are frequently logistic as well. Quite a few organ donors begin their career in an institution at some distance from those in which the recipients are located. Many of these hospitals do not have the sub-specialty physicians or complex laboratory facilities to treat medically prospective organ donors or determine whole brain death. Their intensive care space is limited and can be severely taxed by the presence of a brain dead patient who requires this kind of care and monitoring for periods of time which can run from a few hours to one or two days. The presence of prospective donors in an ICU can, potentially, by taking up a badly needed space, place at risk patients who will recover from their illnesses. Since costs can be high for donor maintenance, reimbursement or its lack can influence the willingness of staff to become involved in this aspect of organ transplantation.¹⁴ The voluntary nature of the organ donation program within a single institution creates an

ambiguous situation with regard to participation. It becomes difficult to justify training of personnel to deal with procedures that may occur only a few times a year.

The creation of regional organizations to assist in donor care is one solution to this set of logistical problems; this response undoubtedly produces greater efficiency but at increased overall cost. Slightly less productivity may in fact be defensible in a system which is under budget constraint because it reduces total expenditures for transplantation. It could be argued that the loss of donors can be rationalized on the grounds that supply will always be less than demand,¹⁵ and deaths within the ranks of potential recipients are inevitable. In which case, a more pressing issue is that of fair allocation of those organs which do become available. The point of this discussion is that an organizational fix is not necessarily a solution to the donor shortage even though it may lead to an increased number of organs being available.

There is an important negative role which donor protocols must fulfill. This is to make sure that recipients are not placed at further risk through receiving an organ which is damaged or from a donor who has an illness which will be lethal to someone who is immunosuppressed. Screening for HIV, Hepatitis B, TB and cytomegalovirus are among current practices. At present positive titres for HIV and Hepatitis B are cause for rejecting a donor,¹⁶ and there is reason to hold that CMV positive donors should not give organs to CMV

negative recipients, while other less stringent factors such as age are relative to the organ involved. In the case of hearts, donors originally were less than 35 years of age, but increasing need has forced several centers to accept healthy donors in their fifties who have received a heart catheterization. Hearts from persons who have coronary disease have been used in emergencies as a bridge until a more suitable donor became available.¹⁷ It is not an unreasonable presumption to conclude that a number of older persons should be considered as sources for hearts as well as kidneys, but their acceptability would depend upon much more aggressive treatment than is currently the practice, in addition to the added expense of the high technology testing which would be required. It may be that faced with the prospect of immediate death, recipients could feel that other current counterindications for donation should be eased such as, for example, a positive HIV titre.

There are a number of legal questions which the care of persons having usable vital organs raises. These relate to the legality of "brain death" criteria for definition of legal death; rights and controls governing the use of human tissue; the use of bodies in those circumstances which require the intervention of the coroner; instances in which minors are implicated. In Canada, as of this time, only the province of Manitoba has followed the recommendations of the Law Reform Commission of Canada and enacted legislation which makes whole brain death a part of the legal definition of death in its

jurisdiction. All the other provinces follow the definition of the Law Reform Commission without as yet having enacted formal legislation.

For all purposes within the jurisdiction of the Parliament of Canada, (1) a person is dead when an irreversible cessation of all that person's brain functions has occurred. (2) The irreversible cessation of brain functions can be determined by the prolonged absence of spontaneous circulatory and respiratory functions. (3) When the determination of the prolonged absence of spontaneous circulatory and respiratory functions is made impossible by the use of artificial means of support, the irreversible cessation of brain functions can be determined by any means recognized by the ordinary standards of medical practice.¹⁸

It is interesting to note that in the absence of special legislation regarding whole brain death, Canada has been free of any challenges to this practice, at least as it has affected transplantation. This is in marked contrast to the recent controversy in Great Britain which was instigated by a group of practitioners regarded as specialists in this matter.¹⁹ It may be that the publicity and acceptance given to the Harvard Criteria, as well as the United States Presidential Commission Report of 1983, Defining Death,²⁰ has done much to allay fears that patient interests could not or would not be protected in this crucial matter. The quickness which physicians and surgeons involved in transplantation provided professional guidelines for the protection of patients who might be potential donors, may also have been a factor in maintaining confidence within the profession that these issues were well in hand.²¹ There has been some speculation that adoption of uniform legislation on death

determination across Canada might provide added incentive for making vital organs available but there would seem to be more compelling reasons to account for their supply being consistently below optimum projections.²²

In Canada, it is the provinces (like their U. S. counterparts, the states) which are responsible for legislation dealing with the donation of organs. In every jurisdiction except Quebec this is accomplished through a Human Tissue Gift Act which was recommended on Federal initiative. In Quebec, Articles 20-23 of the Civil Code make essentially the same provisions. The most important sections for our purpose are those ~~which detail~~ the consent required for either inter vivos or post-mortem donation. It is only the latter which applies to heart transplantation. Consent is said to have occurred when a written notice exists or oral consent is given in the presence of two witnesses during the time of the last illness. (It is the practice but not the law that permission is obtained also from the deceased donor's family.) The Report of the Working Group to which we have referred repeatedly comments on this custom:

Although this practice may be necessary for humane purposes, it reduces the number of donors as many doctors and nurses are hesitant to approach a grieving family to ask for permission to remove vital organs.²³

Two provisions in the Quebec Civil Code allow some discretion to the physician with regard to removal of organs without consent:

A physician may remove a part of the remains, if in the absence of instructions by the deceased, he obtains the consent of the consort or nearest relative of the deceased.

This consent is not necessary when two physicians attest in writing to the impossibility of obtaining it in due time, the urgency of the operation, and the serious hope of saving a human life.²⁴

Whereas the Human Tissue Gift Act does make provision for consent (in the absence of known expressed wishes to the contrary by the deceased) by relatives,²⁵ it has no emergency clause as found in the Quebec Civil Code. In practice, this means that the initiative for donating organs must come in most instances from doctors, nurses or other personnel in the hospital where the patient is. Again, as noted above, the reluctance of medical staff to make such requests is a principal reason for the relatively low rate of organ donation as compared to the number of potential donors.²⁶

The Act establishes several safeguards for the protection of the donor and his identity:

7(2) No physician who has had any association with the proposed recipient that might influence his judgment shall take any part in the determination of the fact of death of the donor.

(3) No physician who took any part in the determination of the fact of death of the donor shall participate in any way in the transplant procedures.

11(1) Except where legally required, no person shall disclose or give to any other person any information or document whereby the identity of any person:

a) who has given or refused to give a consent;
b) with respect to whom a consent has been given; or
c) into whose body tissue has been, is being or may be transplanted,

may become known publicly.²⁷

It has been argued²⁸ that some flexibility should be provided for in the confidentiality requirement and this is the case

in British Columbia. This permissiveness assumes some importance for the discussion of practices for marketing the importance of organ donation.

All jurisdictions make provision for obtaining a coroner's release to remove the organs when the death may result in requiring the body as evidence. This is an important exception because many potential donors are the victims of accidents where inquests or possible criminal charges could result; and wherever possible, it should be accepted that a further injustice should not result from unduly restrictive application of the laws of evidence.

Minors and mentally incompetent persons are cited for special protection in many expressions of the law affecting medical care. Organ donation is no exception. Currently only Québec makes provision for minors "capable of discernment"²⁹ to donate non-regenerative tissue, including inter vivos disposal, as long as this is done,

With the authorization of a judge of the Superior Court and with the consent in writing of the person having paternal authority, provided that no serious risk to his health result therefrom.³⁰

The immediate ethical question that is inherent in the Québec law is the matter of what constitutes no serious health risk. The present state of knowledge does not allow a definitive response to the proviso and thus what may be legally possible is probably ethically undesirable. On the other hand, there does not seem to be a serious question about the potential of a minor to give knowledgeable consent or even request for

post-mortem donation. The debatable point is probably the age at which this should be allowed. The age at which minors can obtain medical treatment without parental consent would be consistent with much current thinking about the capacity for children to exercise reasonable judgment.

More important is the parental role in providing donation of organs in children with severe handicaps, such as anencephaly. At issue here is the kind of problem which children in this condition present to those who are interested in transplanting hearts and livers into very young children. Two issues emerge immediately: what kind of a condition is anencephaly,³¹ and how does its appearance affect the determination of death which is a prior condition for organ donation? These questions answered, another set appears which concerns our abilities to respect simultaneously the person of someone who has no way to live and the desperate situation of those in need of a heart or liver. The discussion stimulated by these concerns is still unresolved and serves as an illustration of the dependency of current ethical debate on the state of knowledge which exists.

The debate about the condition known as anencephaly has enabled a certain amount of clarification to emerge. This is largely the result of the care in which two of its major participants, Alexander Capron and Arthur Caplan have developed their positions. Capron argues for what seems to be the majority when he states that breathing anencephalic newborns are dying not dead and it would be misguided and

destructive to amend either our brain death laws or The Human Tissue Gift Act to permit harvesting organs from live anencephalic newborns. Rather, he believes:

Medical ingenuity should be directed toward finding ways to care for dying anencephalic (and other) babies so that when they become brain-dead, they can be organ donors.³²

Caplan believes some different principles emerge from the facts which describe anencephaly and postulates that newborns with this condition should be considered a separate category of human which he titles "living but brain absent."³³ This being the case parents should be able to donate their newborn's organs prior to their death. His justification is developed on the basis of what might be termed a comprehensive assessment of the meaning of anencephaly:

- a) such children can never develop even "a semblance of personhood."
- b) the need for these organs is real
- c) many parents are eager to have their dead or anencephalic child used as a donor in the hope that something good might come of a tragic situation.³⁴

For the time being, it would appear that Caplan's suggestion has been shelved by events which have taken place in London, Ontario.³⁵ A group of physicians at Children's Hospital decided to carry out research necessary to establish a clinically valid procedure for declaring anencephalic infants brain dead.³⁶ The group was successful in applying this research protocol to an infant known as Baby Gabriel who was pronounced dead and then flown to Loma Linda, California, where her heart was successfully transplanted into a baby

born prematurely by caesarean section so that his hypoplastic left heart could be replaced. The protocol itself by which this event was accomplished deserves careful scrutiny:

Prior to birth the parents agree that:

1. The infant will be resuscitated;
2. Periodic testing will be done to determine brain death (removal from the ventilator at six-to-twelve-hour intervals for a ten-minute period to determine ability to breath spontaneously;
3. Organ donation is acceptable;
4. A definite time limit (to be determined by the parents but not more than fourteen days) after which the infant will be removed from the ventilator and permitted to die. Low dose morphine is administered to prevent potential suffering on the part of the infant, although whether anencephalic newborns can suffer is unknown.³⁷

The success of this protocol may have ruled out for the time being Arthur Caplan's contention that there are specific categories of persons who are legitimate donors for whom the brain death criteria may be inappropriate. His argument may be held to be ethically too risky or contentious because it would require changes in the law, nevertheless, it is essential to realize that there is an ethical cost inherent also in the current stance. George Annas has called attention to these issues in a recent article;

... there has never been a clinical trial to determine how anencephalic infants do with full ventilator support. They have also never been so supported, primarily because the condition is quickly and universally fatal. As one pediatric intensive care specialist put it, it would be "futile and inhumane" to support respiration in these infants artificially. How can we determine if this research is legally and ethically proper?

First, we must determine if it is proper to use dying newborns to help others rather than as ends in themselves Specifically, since anencephalic newborns are not routinely resuscitated, incubated, or

placed on ventilators and given other support, we cannot justify these interventions as "treatment" for these infants. Rather these interventions can only be seen as treatment for the benefit of the ultimate organ recipient, and perhaps as treatment for the parents. If we determine that it is never ethically appropriate to prolong an unconsenting person's dying process for the sake of another, then our inquiry is at an end. If we conclude that it may be appropriate to do so (for example, if the harm to the dying child is trivial and the benefit to others is enormous), we can go on to the second step.

This second step would entail research, like that underway in Canada, to determine: how long anencephalic infants can survive with the support available in an intensive care unit; whether they feel pain or have other sensations; the state of their kidneys, liver and heart, which will determine their general usefulness for transplantation; and whether it is true that the condition of anencephaly can be easily and accurately distinguished from all other abnormalities of infants.³⁸

There is the need for further commentary on the dizzy pace of events represented in the discussion of anencephalic donors. The response thus far, which has been based upon Capron's conservative description of the issues presented by the anencephalic newborn, requires for its realization a series of clinical experiments that are anything but conservative in their ethical implications. As Annas notes, they probably cannot be done legally at the present time in the United States.³⁹ In addition, a major justification for using anencephalic donors, the success of transplantation in infants, is quite unproven. This is probably less so for its efficacy, but very much the case for its effectiveness as we have noted elsewhere.⁴⁰ In addition, there is the question of how many anencephalic newborns will ever or should ever be available for organ donation considering that many are stillborn and most others may be detected at a

point in the pregnancy when therapeutic abortion is a possible and reasonable option. It would then fall upon obstetricians to persuade women who are pregnant with a fetus in this condition that they should "risk" carrying it to term because a transplant is a way to make something good out of this tragic event.⁴¹

Under such circumstances, Arthur Caplan's analysis does not appear to be quite so radical as initially received. He has perceived that the whole situation surrounding anencephaly in newborns presents a condition which is more unique than not. He has argued that the best response to this state of affairs may not be searching for what this event has in common with others (a quest not unlike that made by traditional and modern casuistry⁴²) but by defining what is different, and using this as the principle for understanding and regulating our response to these new facts. The advantage of this approach is that it appears to be more cognizant of the real meaning of transplantation -- the spare parts concept -- which changes a number of traditional points of view, including the way we approach death. While not wishing to imply the concept of "brain death" should be abandoned, it is worth considering whether or not it meets totally the legal and human needs that the act of transplantation creates. Put in terms of the argument presented in this dissertation, the transplantation of very young infants represents an attempt to "buy" a normal lifetime for someone who would otherwise die very quickly. The use of anencephalic newborns as donors offers the opportunity to see if this is

actually possible. Do experiments for determining how brain death may be established really touch the magnitude of the moral and ethical issues involved? It is fascinating why we consider it more important to offer protection to that member of society who will never live while the fate of the recipient is casually dismissed. Another agonizing set of circumstances to which Caplan has called attention is that of parents who see in organ donation an opportunity to lessen the tragedy of untimely death. The giving of time to another through organ donation presents a challenge to traditional cultural and religious understanding of what it is to die.

This has yet to be assimilated. It is so far unclear how far it is possible to make use of this potential or what ethical limits should be placed upon its undue exploitation.

3. How many potential donors are actually present? It has been argued on other grounds that this natural limit puts a lid on the indefinite expansion of the costs of transplantation to our health care system.⁴³ There are conflicting conclusions as to whether this natural limit establishes a perpetual shortage of organs or represents a temporary condition.⁴⁴ Arthur Caplan has suggested that demand is a function of supply and will have no theoretical limit, so is an illustration of how doctors effect these statistical projections.⁴⁵ Whether all or only some of these conclusions are true does not change the fact that the success of transplantation has created a great demand for organs and led to thinking about the efficiency, real and potential, of our

system for recovering vital organs from the dead. In Canada this attempt has been made quite recently by The Minister's Task Force on Kidney Donation.⁴⁶

a) The Magnitude of the problem which confronts our health care system ... There are currently 156 persons per million population on dialysis in Ontario. The typical patient is aged fifty and can expect another twenty years of life.⁴⁷ There is considerable evidence that most of these patients would have a better quality of life at less expense to the Health care system if they could have a cadaver donor kidney transplant.⁴⁸ The current rate of kidney transplantation in the province is 29 per million population which leaves a considerable gap between those treated with transplantation and those who could be. It is estimated that about 66% of new cases of ESRD could be treated with kidney transplants.⁴⁹ What the possible difference in cost effectiveness is between the two approaches to ESRD is somewhat problematic since the types of dialysis and its locale affect its cost.⁵⁰ However, the average cost per patient of \$40,000 annually in 1984 dollars⁵¹ means that the \$25,000 average cost of a transplant appears to offer some promise of savings on a per patient treated calculation. In addition there are reports of greatly improved quality of life in transplant recipients.⁵²

b) How do these results and calculated needs appear in the face of actual and projected donation of organs? ... In the case of kidneys, the calculation shows that with 93 deaths per million population under age 65, with a diagnosis which

makes their organs appropriate for transplantation, there could be over 4,500 kidneys available to meet the demand of 1250 kidneys for the year 1990.⁵³ This comes out to mean that about 1.3% of all hospital deaths were seen as potentially suitable kidney donors. Similar studies in the United States by the Center for Disease Control show that among deaths in the age range birth to 65 years, there were potential donors of 116 per million population giving a total of 27,000 nation wide. However, there were only 3,681 cadaver kidneys transplanted.⁵⁴

c) Data which may be applied to heart transplantation in Canada ... Estimates of the level of need have been shifting due largely to improved survival statistics which allow for considering transplantation as a preferred treatment for a wider range of the cause of ESHD (End Stage Heart Disease).⁵⁵ In trying to account for these shifting practices the Report of the Working Group, previously cited, projected a rate of 18 per million population as a reasonable estimate of anticipated Canadian practice.⁵⁶ Using a population of 27.5 million as a base, this suggests that 495 heart transplants per year might be appropriate for Canadian practice. Determining the number of potential donors was more difficult but assuming the current practice of restricting suitable donors to persons under 40 years of age, their figures suggested 700 hearts could be expected to be available yearly at some point in the future.⁵⁷ Actual figures for 1986 show that the real rate of transplantation was about 25% of that which might

reasonably be projected as desirable, and this was an accurate reflection of donor availability, the latter running at about 17% of projection.⁵⁸ That the Canadian figures as to the rate of potential donors are conservative is strongly suggested by a note found in Appendix G of the Report:

Studies in the United States give figures for potential donors among hospital deaths ranging from 0.77% to 3.5%. These figures, at their lowest, are ten times as high as the figures the Working Group has used.*⁵⁹

How are we to interpret the difference which exists between the number of organs currently available and those developed from projections In its report the Ontario Group has identified a number of failures in the current system which could account for much of this discrepancy.

a) It needs to be recognized that most organ donors are found among the victims of four causes of death: I. brain tumor; II. head trauma, brain injury, aneurysms, etc., III. asphyxia; and IV. poisoning.⁶⁰ At the present time, most persons who are potentially suitable organ donors are in large tertiary care hospitals and thus relatively concentrated as to their location.⁶¹ Yet a study of a number of representative institutions in this category showed that about 50% of potentially suitable donors were never identified and thus never had the opportunity for further follow-up.⁶² These findings point to the existence of significant responsibility for these low donation rates must fall upon the professional staffs in these institutions and that both attitudinal and informational factors are involved.⁶³

b) Among the potential donors who are identified, a significant number is missed because consent for donation is never obtained from the relatives. This has been called by many who are knowledgeable "the failure to ask." The most potent contribution toward this negative response is the feeling of doctors and nurses. Approximately 50% felt they were "bothering" a grieving family by initiating a request for donation.⁶⁴ There is, in addition, a number of more strictly professional sources for the failure to ask. These include the absence of a clear policy in the hospital which would facilitate organ donation and which results in confusion among staff as to what procedures are to be used. The organ donation process is viewed as being extremely disruptive and time-consuming for those responsible for patient care in an ICU or Recovery Room with more than 75% of doctors and nurses in one survey indicating that time demand was a real barrier to participating in the organ donation process.⁶⁵ Lack of knowledge as to what constitutes appropriate organ donors may also be a factor, particularly as this is expressed along with the need for more in-service training, general lectures and information. For non-transplant hospitals, the donation process can impose a burden on ICU budgets if a reimbursement program is not in effect. The same concern was raised over physician time spent with a donor which is often not reimbursed.⁶⁶

Next in the magnitude of effect would appear to be the public's attitude toward organ donation. This may be

summarized as being inconsistently in favor of donation; being somewhat confused about the role of donor cards and adamant in believing that the present system of encouraged voluntarism is the desired method for obtaining organs. There was a feeling that publicity about the success of transplantation and the need for donor organs would be valuable.⁶⁷ Thus, it is not surprising that among professional staff surveyed about current barriers to donation, 90% listed relatives as the principal factor for refusal and over 80% stated they had had an experience with a family refusing consent.⁶⁸ Hospital experience at best is difficult to document and it may be that what these last statistics indicate is the extent to which negative experience tends to dominate our thinking on a matter about which we have ambivalent feelings. Reviewing the evidence available on why there is such a high failure to obtain consent, it would seem that not enough has been made of the complex motives which inspire voluntarism and therefore the factors cited are classified much too crudely. One illustration of this tendency may be found in the absence of ethnic and cultural data on those who refuse, i.e. the attempt to subsume this kind of information under the categories of fatalism and superstition and/or religion⁶⁹ represent bad research technique. Another issue may be the special role which transplantation as a technology demands from its practitioners. As in the case of many of the medical staff who are involved in providing therapeutic abortions to women in need, they find themselves placed in a humanly impossible

situation by offering a service which can earn them the gratitude of those who receive it while having to deal at the same time with the loss of another life.

Consent request is essentially straightforward if the person is already brain dead, but, at what point in the stage of potentiality is it acceptable to obtain written consent for organ donation? Since this consent is vital if a patient is to be transferred to a facility equipped for transplantation, special care must be taken to have responsibility in the hands of physicians who are independent of the transplant team. This is a practical consideration, since many institutions are reluctant to commit ICU beds to patients when consent for donation is problematic. Since the category of potential donor is really a function of accurate prognosis, it is reasonable to expect standards to be developed for making this decision. As we have seen, this is another illustration of the way in which use of the body as a source of spare parts makes of the dying and death of some persons a special act unique in human experience.

c) What kind of an organizational structure will facilitate organ donation ... The general feeling is that organ retrieval is improved if it is organized on a regional and national basis.⁷⁰ Typical of such response is the More system for the Province of Ontario and Metro Transplant which serves the same function in Quebec. Full time coordinators and secretarial staff, supplemented as necessary by part-time on-call assistance, make it possible to get

information and assistance for organ donation and retrieval on a round-the-clock basis every day of the year. These organizations are responsible also for educational programs within institutions as well as more general information to the public at large. They maintain and coordinate the list of potential recipients on the waiting list for vital organs which includes kidneys, hearts, heart and lung, isolated lung, pancreas and livers. A role of some importance, from an ethical point of view, is played by the waiting list which governs how organs are allocated.⁷¹

In depending upon a voluntary system to supply organs for transplantation, it is essential that those who are expected to contribute believe that the system of allocation is fair and just.⁷² But what constitutes fairness? Is it making sure that organs are given to those who have the best chance of surviving with a reasonable quality of life? Is it based upon who has been waiting the longest or who is the sickest and most needy? For how much should the HLA match count when it is applicable (viz. at the present time mainly for kidneys)? Who should decide which system to use when the criteria may be only incidentally medical? Where ABO blood group compatibility is essential, what use should be made of Group O donors? (They are compatible with the other 3 groups and the use of these organs in this way discriminates against the person who is waiting for a Group O organ). When the supply of organs exceeds the demand, is the rule of fairness altered by the fact that the waiting list is not just a

way of getting an organ sooner rather than later, but a source of false hope, with many on it scheduled to die?⁷³ Under such circumstances, is a form of random selection preferable to a priority system which can always be manipulated? Does keeping the waiting list deliberately short constitute a fair way of responding to a shortage of organs? (rationing by refusal to consider for selection).

Every category of organ being transplanted presents its own set of characteristics which must be respected in devising a system of fair allocation. This caveat will be respected as we examine some of the current issues in the distribution of hearts. Transplantation is the final stage in a process that includes referral, evaluation and selection. As the result of greatly improved survival of those who are transplanted: there are more conditions of end-stage heart disease for which transplantation is a treatment of choice; a wider range in the stages of ESHD at which patients are selected; thus, criteria for priority have been developed which are an attempt to improve on the crudeness of first come, first served (length of time on the waiting list). This standard served initially as the basis for allocation and was reasonable so long as there were enough hearts available to meet the demand. It was the equilibrium of need and supply which made it permissible to create categories of "super" need composed of patients in the ICU on maximum life support or on an artificial heart "bridge" device. Ostensibly, all this did was to extend the waiting time for those persons who were

not quite so sick, but what this did was to give hospitalized patients an advantage over those at home, ignoring the fact that many of these persons were at high risk for sudden death particularly with extended waiting times. Need defined as hospitalization is not a fair reflection of prognosis when there are not enough organs to go around because it is not an accurate depiction of the risks of end-stage heart disease. Nonetheless, it has become the standard for determining patient priority on the waiting lists which are the responsibility of the Regional or even in some instances, National systems for organ retrieval and distribution.

The creation of a system which is particularly responsive to conditions of urgency is open to manipulation often to the detriment of those who are not benefitted by the criteria. Not only that but the classes of priority do not really have much scientific basis because they equate hospitalization as an indicator of prognosis.⁷⁴ It cannot help but encourage ingenious ways of queue jumping because our Health care system has been taught that medical need has near absolute priority. This has been frequently true of conditions involving children.⁷⁵

The other question raised by the effort to maximize the number of donors is: has it led to an ideal rather than to a reality of current availability in establishing the ethical norms for organ allocation?⁷⁶ The whole system is organized as if there are enough donors. The shortfall produces increased efforts at getting more organs, but only apologies

to those being victimized by this Alice in Wonderland attitude to failure. It is not good enough to inform patients on a waiting list that they may not get an organ in time, when this statement is more true for some patients than others. The ethos of voluntarism has an effect upon how failure is regarded in this system and imposes limits as to how much can be done to rectify the situation. If this is the case, it must be accounted for in a distribution system committed to justice and fairness. While a lottery appears crude and at odds with the altruism on which our acquisition system runs currently,⁷⁷ it may represent a more just system for buying time.

4. To meet the challenges it faces, institutionalized voluntarism in North America has turned to increasingly sophisticated marketing techniques. Organ donation is no exception. Surveys have indicated that both professionals and the general public want more information about transplantation and the process of organ donation.⁷⁸ Other efforts have been directed to selling donation as an act of human generosity and have suggested that even in a time of tragedy, organ donation can help those involved feel better.⁷⁹ There is a danger that ethical pronouncements, made by physicians involved in transplantation, which are ostensibly to reassure themselves and others that the practice is morally acceptable, can and would be regarded in most other circumstances as more like marketing techniques aimed at selling a product.⁸⁰ One advantage of proposals for

"required request" laws⁸¹ is that while they require knowledge and good will on the part of the general public for their ultimate success, they are able to direct energies from selling and marketing to more professional activities of informing and counselling those for whom fate has given a chance to donate organs. Their effect is to require developing more a new class of professionals who must bear the burden of "securing" the organ supply in a way which does not violate their humaneness and which respects the integrity of those suddenly given the opportunity to donate.⁸²

5. Alongside of the formal institutions which are responsible for organ donation, a number of special interest groups has arisen. These groups have a specific mission to sensitize the general public to the virtues of organ donation. Foremost among them in Canada is Transplant International whose publication, Transplant Lifelines reflects its dedication to "promoting public awareness and support for organ donation throughout Canada."⁸³ This group has shown an interest in bringing together families of donors with recipients as a visible way of demonstrating the therapeutic effect of organ donation. Its publications include testimony from donor families as to the positive value of organ donation on their grieving and loss. It has encouraged the families of donors to break the anonymity assigned them by the Human Tissue Gift Act and a number of provinces have amended their laws to make this action legal. The appeal of this approach is obviously very meaningful to many persons, although care must

be taken to avoid placing a burden on a recipient to live up to the expectation of a donor's family or feel an emotional obligation to someone with whom he has been united by chance.

Recipients of transplants have organized themselves and included in their activities have been efforts to encourage organ donation by citizenry at large. In England and on the Continent, heart recipients stage Field Days and even Marathons to help publicize the positive effect of transplantation and to encourage the signing of donor cards. In Quebec, the Association des Greffés du Coeur Inc. has been instrumental in persuading the Provincial Government to have places to indicate on both Driver's Licenses and Medicare Cards that organ donation is desired. The group appears regularly on Telethons and public gatherings to stimulate awareness in the virtue of organ donation. It publishes a newsletter, l'p'tit coeur,⁸⁴ which keeps its members informed of the latest developments in heart transplantation and includes a variety of items encouraging them to keep fit. An offshoot of the association of persons having had a transplant is the individual who makes a career out of this fact. Diane Hebert,⁸⁵ a young Montreal woman, has been very active in promoting the cause of transplantation and organ donation. Since her transplant in 1986, she had devoted her life to this work. She has helped create a number of charitable foundations to help purchase equipment for hospitals providing this service in Québec and is a source of immense hope to those persons who require a heart and lung transplant. All

of these approaches stress the personal elements that abound in this experience and serve to give an important dimension of credibility to the lobbying which has become a necessity in the quest for a share of health care dollars.

This survey has tried to show the scientific, human, organizational, emotional, medical and ethical complexity of organ donation. It is the less visible part of transplantation because its most important participants are by their nature no longer with us. It is the most challenging because it involves doing what has not been done before while seeking at the same time not to lose touch with the values of the human community which it depends upon for approval. The currency which it uses is time. The commerce which it stimulates involves a trade which is unique in human experience.

Footnotes to Chapter VI

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⁶R. Fox and J. Swazey, The Courage to Fail, p. 5.

⁷Paul Ramsey, The Patient as Person (New York: Yale University Press), 1970.

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¹⁴M. A. Robinette; et al., "Donation Process," Transplantation Proceedings, Vol. XVII, No. 6, Supplement 3, December 1985, p. 53.

¹⁵M. Miller, "A Proposed Solution to the Present Organ Donation Crisis Based on a Hard Look at the Past," pp. 20-27.

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²¹ This was accomplished by offering public support for controls being incorporated in legislation such as the Uniform Anatomical Gift Act in the United States and the Human Tissue Gift Act in Canada.

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²³ Working Group on Vital Organ Transplant Centres, Report, p. 55.

²⁴ Quebec Civil Code, Article 2.

²⁵ Part II, Section 5.

²⁶ Task Force to Investigate and Develop Methods of Increasing Kidney Donations for Transplantation, "Summary of Task Force Findings," Transplantation Proceedings, Vol. XVII, No. 6, Supplement 3, December 1985, p. 9.

²⁷ Uniform Human Tissue Gift Act in Working Group on Vital Organ Transplant Center, Report, Appendix 1, pp. 174ff.

²⁸ Ibid., p. 57f.

²⁹ Civil Code of the Province of Quebec, Article 20.

³⁰ Ibid., Article 20.

³¹Unlike nearly every other handicapped newborn, there is general agreement that they need not be treated in order to prolong their lives, c.f. G. Annas, "From Canada With Love," Hastings Center Report, Vol. 17, No. 6, December 1987, pp. 36-39.

³²A. Capron, "Anencephalic Donors . . .," Hastings Center Report, Vol. 17, No. 1, February 1987, pp. 5-8.

³³A. Caplan, "Should Fetuses or Infants be Utilized as Organ Donors?" Bioethics, 1, No. 2, February 1987, pp. 119-140.

³⁴Ibid., pp. 122ff; G. Annas, "From Canada With Love," p. 37.

³⁵However, whether this discussion will lead to a more general debate on the definition of death which is acceptable in our society seems very likely to many including Caplan (personal communication). The issue is already launched in a number of books and articles viz. Karen G. Gervais, Redefining Death (New Haven and London: Yale University Press, 1986). What is not so clear is the extent to which it will be welcome to those involved in the care of prospective donors, nor has it been considered what effect this redefinition of death will have at the other end, namely, the beginning of a legally recognized human life.

³⁶G. Annas, "From Canada With Love," p. 36.

³⁷Ibid., pp. 36-39; a similar experiment in the U. S. at Loma Linda, California was reported in the New York Times, December 10, 1987.

³⁸G. Annas, "From Canada With Love," p. 37.

³⁹Ibid., p. 37, although since then, as we have seen, the physicians at Loma Linda have decided to try.

⁴⁰Viz. Chapter V, p. 158.

⁴¹G. Annas, "From Canada With Love," p. 39.

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⁴³R. W. Evans, "Donor Availability as the Primary Determinant of the Future of Heart Transplantation," JAMA, Vol. 25, No. 14, April 11, 1986, pp. 1892-1898.

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⁴⁷M. A. Robinette and C. R. Stiller, "Background to the Task Force: Health Care and Financial Implications," p. 5.

⁴⁸Ibid., p. 7.

⁴⁹Working Group on Vital Organ Transplant Centres, Report, Appendix F, p. 135.

⁵⁰R. D. Guttman, "Renal Transplantation," New England Journal of Medicine, Vol. 301, November 1 and November 8, 1979, pp. 975-982 and 1038-1048; R. R. Bovbjerg, et al., "Provider-Patient Relations and Treatment Choice in the Era of Fiscal Incentives: The Case of the End-Stage Renal Disease Program," The Milbank Quarterly, Vol. 65, No. 2, 1987, pp. 177-202; A. Caplan, "How Should Values Count in the Allocation of New Technologies in Health Care?", in R. Bayer, et al., In Search of Equity (New York and London: Plenum Press, 1983), pp. 95-124; A. J. Wung, "Why Don't the British Treat More Patients With Kidney Failure?", British Medical Journal, Vol. 287, No. 6400, 22 October, 1983, pp. 1157-1158.

⁵¹M. A. Robinette and C. R. Stiller, "Background to the Task Force," p. 5.

⁵²R. W. Evans, "The Socioeconomics of Organ Transplantation," Transplantation Proceedings, Vol. XVII, No. 6, Supplement 4, December 1985, pp. 131ff.

⁵³Working Group on Vital Organ Transplant Centres, Report, p. 17.

54 Ibid., Appendix G.

55 Initially victims of myocardial infarction were not candidates for transplantation. Now they number 50-60% of all cases of heart transplantation. C.f. M. Buxton et al., Costs and Benefits of the Heart Transplant Programmes at Harefield and Papworth Hospitals, pp. 134f.

56 Ibid., Appendix F, p. 136.

57 The date used in the study was 1990.

58 Ibid., p. 17, Appendix G, p. 138.

59 Ibid., p. 138; *that is the Canadian projection quoted above.

60 M. A. Robinette, et al., "The Donation Process," p. 47.

61 Ibid., p. 47.

62 Ibid., pp. 47-48.

63 See below under (b) (c).

64 Ibid., p. 47.

65 Ibid., pp. 51-52.

66 Ibid., pp. 52-53.

67 Ibid., pp. 48-50.

68 Ibid., pp. 50-51.

69 E. Evers, V. T. Farewell, and P. F. Halloran, "Public Awareness of Organ Donation," CMAJ., Vol. 38, February 1, 1988, pp. 237-239.

70 Cf. Task Force on Organ Transplantation, Organ Transplantation Issues and Recommendations, Washington, D.C., U. S. Department of Health and Human Services, April 1986; Task Force on Vital Organ Transplant Centres, Report, p. 6.

⁷¹The complexities in keeping track of the proper order is one of the reasons often cited for having large, computerized regional centers to facilitate allocation. C.f. A. Caplan, "Equity in the Selection of Recipients for Cardiac Transplants," p. 17; T. Starzl et al., "A Multifactorial System for Equitable Selection of Cadaver Kidney Transplants," JAMA., Vol. 257, No. 22, June 12, 1987, pp. 3072-3075, proposes a priority system which includes a scale of need for heart recipients; see also Resolution on Organ Distribution, Council on the American Society of Transplant Physicians, May 26, 1987.

⁷²A. Caplan, "Equity in the Selection of Recipients for Cardiac Transplantation," p. 10.

⁷³30% most recent experience at RVH.

⁷⁴Cf. T. Starzl et al., "Multifactorial System for Equitable Selection of Cadaver Kidney Recipients," p. 3075.

⁷⁵E.g. the Jamie Fiske incident which prompted the creation of the Massachusetts Task Force on Organ Transplantation; or the appeal in Ontario of September 1986 for a liver for a boy from Manitoba which was successful but required by-passing three other children who subsequently died before they could receive an organ. Ironically, the first recipient for a heart from an anencephalic donor had to be specially created, viz. Baby Paul! C.f. George Annas, "From Canada With Love," p. 36; P. Gunby, "Media-Abetted Liver Transplants Raise Questions of 'Equity' and 'Decency'," JAMA., Vol. 249, No. 15, April 15, 1983, pp. 1973-1982.

⁷⁶Cf. "Panel Discussion on Vital Organ Procurement and Exchange," in "Organs For Transplantation," Transplantation Proceedings, Vol. XVII, No. 6, Supplement 4, December 1985, pp. 92ff.

⁷⁷H. T. Engelhardt, Jr., "Shattuck Lecture -- Allocating Scarce Medical Resources and the Availability of Organ Transplantation," New England Journal of Medicine, Vol. 311, No. 1, July 5, 1984, pp. 66-71.

⁷⁸M. A. Robinette et al., "Donation Process," p. 54.

⁷⁹M. Miller, "A Proposed Solution to the Present Organ Donation Crisis Based on a Hard Look at the Past," p. 20.

⁸⁰Cf. C. R. Stiller, "Ethics of Transplantation," Transplantation Proceedings, Vol. XVII, No. 6, Supplement 3, December 1985, pp. 131-138; F. N. McKenzie et al., "Cardiac Transplantation: Ethical and Economic Issues," Transplantation Today, Vol. 2, February 1985, pp. 22-26.

⁸¹Cf. A. Caplan, "Should Hospitals be Required to Ask Families to Donate Organs?", Midwest Medical Ethics, Summer 1985, p. 315; M. Miller, "A Proposed Solution to the Present Organ Donation Crisis Based on a Hard Look at the Past," pp. 21ff; John Robertson, "Supply and Distribution of Hearts for Transplantation: Legal, Ethical, and Policy Issues," pp. 77-87; The Hastings Center, Ethical, Legal and Policy Issues Pertaining to Solid Organ Procurement, October 1985.

⁸²Considerable literature has accumulated on the work of transplant coordinators, c.f. D. W. Denney, "The Non-Physician Coordinator's Contribution to the Development of an Organ Procurement Program," Transplantation Proceedings, Vol. XVII, No. 6, Supplement 4, December 1985, pp. 83-87; several regional Transplant Centers have established training programs which have helped establish the professional status of this occupation.

⁸³From the masthead of Lifelines, address: c/o Transplant International (Canada), 339 Windermere Road, London, Ontario, N6A 5A5.

⁸⁴Association Des Greffes du Coeur Inc., 1445 rue Bishop, Suite 2, Montréal, Québec. H3G 2E4.

⁸⁵Cf. Dianne Hebert, Un Second Souffle, Montreal, Les éditions de l'homme, 1986.

CONCLUSION

FOR ANOTHER TIME

In spite of the fact that it has been quickly assimilated into our expectations of medicine, transplantation remains, as does much of high technology, a demanding intruder into our established values and practices. Not only does it illustrate in a dramatic way the paradox that many of medical technology's greatest accomplishments are limited to a select few; it reveals our desire to provide this advantage to the fortunate few at almost unlimited cost. But can our society escape with such a simple approach to fairness and justice when our most unlimited resource -- money -- is also in restricted supply? Everyone seems to agree that physicians are incapable of providing answers to these problems of allocating resources, but acknowledges, as well, that neither the political structures nor the health care system is very good at providing answers either. Our times demand an informed public, yet there is little to show for efforts to involve the wider community in the debate which is deemed necessary.

If this were not enough, we discover that transplantation requires organ donors and this forces a reconsideration of much of our collected wisdom about dying and death and the

human potential for rescuing those doomed to die before their time. It is truly remarkable that a legally dead person can supply viable organs to another and this potential is barely explored, if we believe that it makes sense to offer life to another in this way. The go-betweens in this exchange are members of the health professions, and the public expects some indication of what this action means to those in this role. Are they a modern-day version of the body snatchers or are they fellow human beings deeply moved by the awesome responsibility for this exchange of life? Does the reluctance of hospital staff to ask relatives for organ donation mean only a hesitation to break into the grieving process or does it indicate a certain reflexive negative reaction to what they are expected to instigate? For doctors and health professionals to speak more openly about these feelings would undoubtedly help, since our means of securing organs is committed to those who respect the voluntary nature of this action. More needs to be made of the giving rather than the taking part of acquiring organs, and not just in terms of the altruism involved. An increase in donors will undoubtedly require a good deal more social solidarity than is present at the moment, when minority groups are conspicuous by their failure to participate in organ donation.

So far, children and infants have made up a very tiny percentage of those who have received hearts. Those children who have, however, receive the greatest share of the publicity about this operation. Up to now, there has been

almost no mention made of the highly experimental nature of transplantation in children. There is some evidence and much conjecture that their immune systems may be unusually receptive to foreign organs, but it will take a couple of decades to know with any degree of certainty. In the meantime, how do we balance the experimental nature of children's transplantation with the obvious usefulness of it for adults, if we have limited resources? Doctors should not be allowed to make such decisions unilaterally, but how do we go about giving them a social warrant for this kind of undertaking?

Moral calculations of this kind are difficult to make since they require placing value on actions to which humans have previously had no access. Calculable life extension is a concept hardly understood yet we are expected to fill it out as a daily practice as persons are selected to be recipients of a transplanted heart. At the same time, such high technology cannot overwhelm more traditional and necessary medical practice for which there is prior commitment. Information (and the ability to understand its significance) becomes, under these circumstances, a vital commodity, yet we are just beginning to develop decision-making models which are capable of evaluating variables in the quantity with which they are present in these health care situations. These "games" are so attractive in their own right, that they can easily distract the curious and striving who are committed to the improvement of our ability to overcome disease.

The irony of applying high technology to medicine is

that many of its greatest successes are for the select few, yet it is only with the support of all of society that such accomplishments are possible. This is something of a switch, the implications of which have yet to dawn on many health planners who still continue to view technology as capable of mass application. This anachronism is very evident in the projections which have been generated as to the potential of the artificial heart. It is obvious that many cherished values about the social meaning of freedom and autonomy require a definition which goes beyond the pastoral setting out of which they have sprung, and reflects instead complex post-industrial society set in the midst of the gaping poverty of the Third World.

Although our Christian religious tradition has often been viewed as offering essentially a negative view of scientific accomplishment, this is not its only stance. It does offer a radical sense of the future which requires of human beings that they be responsible for providing for yet another generation. This vision is a chance for both individual opportunity and communal solidarity as those who are a part of the Body of Christ have always insisted. The newness in all this is the willingness to share this hope without requiring simplistic conformity or engaging in a colonialistic conquest.

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APPENDIX

These questions are part of a study which is to be included in a Ph.D. dissertation concerned with the effects of high technology upon the practice of medicine.

I am interested particularly in discovering how physicians (Cardiologists) view their participation in a treatment procedure (Heart and Heart/Lung Transplantation) which requires a series of complex evaluations for its successful realization. Another study will be made of patients to determine how they understand and evaluate their experience as potential and actual transplant recipients.

As you are aware, organ transplantation is being done in many centers world-wide. This study will not try to evaluate or compare different institutions. It is an attempt to look at the larger social setting of organ transplantation.

The following questions are intended to explore the referral networks which furnish patients for heart and heart/lung transplantation.

1. What are your feelings about the value of transplantation as a medical treatment?
2. What are the medical conditions which would lead you to refer someone for heart or heart/lung transplantation?
3. What factors, to your mind, might preclude your considering a patient for referral?
4. What seems to you possible negative effects of transplantation upon the recipient, e.g. medically, psychologically, socially?
5. Is there, from your point of view, an ideal patient (psycho-socially) for transplantation?
6. What is your attitude towards immuno-suppressant therapy as a long-term practice?
7. How do you regard the practice of re-transplanting previous recipients? What criteria should be used in assessing the desirability of doing a re-transplant?
8. How do you think most patients react psychologically to the presence of another person's organ in their bodies?

* * * * *

1. What have been the sources of your information about transplantation and the local centers which offer it?

2. What are your expectations with regard to feedback from the transplantation centers to which you might refer/ have referred patients?
3. What kinds of benefits do you see justifying a heart, heart/lung transplantation program from the point of view of society and the use of scarce resources such as money and organs?

* * * * *

1. What is your attitude toward donating your own organs?
2. From what you know about the current state of the procedure would you think of yourself as a possible heart or heart/lung recipient should the need arise?

Les questions suivantes font partie d'une étude réalisée dans le cadre d'une thèse de doctorat portant sur les effets de la haute technologie sur l'exercice de la médecine.

Je cherche plus particulièrement à découvrir comment les médecins perçoivent leur participation à un traitement (transplantation cardiaque ou cardio-pulmonaire) qui exige une série complexe d'évaluations afin d'en assurer la réussite. Une autre étude sera réalisée auprès des patients afin de déterminer comment ils comprennent et évaluent leur expérience à titre de receveur d'organe potentiel ou actuel.

Comme vous le savez, des transplantations d'organes sont réalisées dans de nombreux centres partout au monde. Cette étude ne tentera pas d'évaluer ni de comparer ces diverses institutions. Je veux plutôt étudier le contexte social global dans lequel s'inscrit la transplantation.

les questions suivantes visent à explorer les réseaux de références qui proposent des patients à la transplantation cardiaque ou cardio-pulmonaire.

1. Quels sont vos sentiments à l'égard de la valeur de la transplantation à titre de traitement médical?
2. Quelles sont les conditions médicales qui vous mèneraient à proposer qu'une personne subisse une transplantation cardiaque ou cardio-pulmonaire?
3. Quels facteurs pourraient vous empêcher de proposer qu'un patient subisse une transplantation?
4. D'après vous de quel ordre seraient les effets négatifs possibles d'une transplantation sur un receveur?
 - a. médical
 - b. psychologique
 - c. social
5. D'après vous, existe-il un patient idéal du point de vue psychologique et social pour subir une transplantation?
6. Quelle est votre attitude à l'égard de la thérapie immunosuppressive à titre de traitement à long terme?
7. Comment percevez-vous la pratique de retransplantation chez des receveurs antérieurs? Quels types de critères devraient servir à évaluer si une retransplantation est souhaitable ou non?
8. Comment croyez-vous que la plupart des patients réagissent psychologiquement à la présence du coeur d'une autre personne dans leurs corps?

1. Quelles sont vos sources de renseignements sur les transplantations et les centres locaux où elles sont réalisées?
 2. Quelles sont vos attentes à l'égard du suivi provenant des centres de transplantation auxquels vous auriez ou pourriez référé des patients?
 3. Quels sont les avantages qui pourraient, à votre avis, justifier la mise sur pied d'un programme de transplantation cardiaque ou cardio-pulmonaire du point de vue social et compte tenu de l'utilisation de ressources rares (argent et organes)?
-
1. Quelle est votre attitude à l'égard du don de vos propres organes?
 2. D'après ce que vous connaissez du procédé tel qu'il est présentement pratiqué, vous considéreriez vous comme un receveur possible d'un cœur ou d'un cœur et de poumons, le cas échéant?