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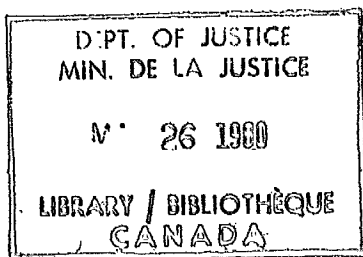
SANCTITY OF LIFE

or

QUALITY OF LIFE

in the context of ethics, medicine and law

Protection of Life Series



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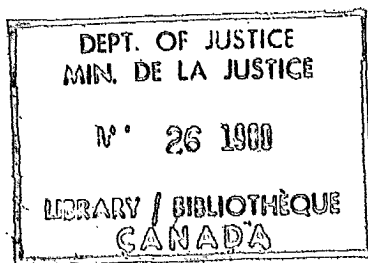
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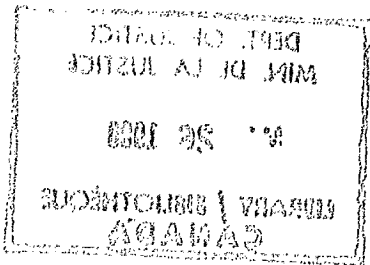
A study written for

The Law Reform Commission of Canada

by

Edward W. Keyserlingk





Notice

The following Study Paper is part of a research project undertaken by the Law Reform Commission of Canada on protection of life issues in the biomedical context.

The author, Edward Keyserlink, is coordinator of the project and in this paper attempts to analyze the concepts of sanctity of life and of quality of life from an ethical perspective as they relate to law and law reform.

The opinions expressed in this Study Paper are entirely those of the author and do not necessarily represent the views of the Commission or of the Commissioners. The Law Reform Commission of Canada would welcome however any reaction, criticism or comments from the reader. They should be addressed to:

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Introduction

Although this paper is written in the context of a law reform project, it is not primarily a legal analysis, nor will it make, at least in legal language, specific law reform proposals. Its more modest purpose is that of a background paper, and its perspective is largely ethical (philosophical and religious).

It seeks to do four things. First of all, to describe and evaluate from that ethical perspective some of the major views and trends today on those related and somewhat elusive subjects of "sanctity of life" and "quality of life" in the medical context. Secondly, to make some reasoned choices and proposals. Thirdly, to indicate some of the implications and priorities of the ethical and value analyses and proposals for law and law reform. Fourthly, to indicate and encourage the interaction of law and morals, yet draw attention as well to the differences in perspectives and priorities.

Whether this particular paper will fulfil those aims and proves to be useful, will be for others to judge. But that law and morals, law and values are in fact related, and that this particular (moral) subject — sanctity of life/quality of life — is central to law and law reform, should need little justification.

Especially since the Hart-Devlin debate, no one would maintain that law (and punishment) should come into play whenever immorality is present. But at the same time, one should want to say that there is no reason for criminal law (and punishment) to be involved *unless* immorality is present. Devlin may have been mistaken about how law and morals are linked to each other, but not that they are linked. This is essentially the view adopted by the Law Reform Commission of Canada in its 1976 Report to Parliament entitled, "Our Criminal Law", when it observes,

In truth the criminal law is fundamentally a *moral* system. It may be crude, it may have faults, it may be rough and ready, but basically it is a system of applied morality and justice. It serves to underline those values necessary or else important, to society. When acts occur that

seriously transgress essential values, like the sanctity of life, society must speak out and reaffirm those values. This is the true role of criminal law. (p. 16.)

Evidence of this interrelationship between law and morals, in reality or in expectation, is near at hand. It may well be that law is somewhat in disrepute partly at least because more and more of our laws have no perceived moral content, and because many acts perceived as seriously immoral and dangerous, are not against the law. Merely regulatory laws multiply with reckless abandon; the involvement of the law in seriously harmful areas is seen as selective and biased — environmental pollution, false advertising and resource prodigality largely escape its wrath; some laws enforce a morality which has considerably evolved since those laws were enacted.¹

Law making and law reform then are in constant danger of appearing to be or becoming only legalistic and uninspiring rule making, unless in some way they refer to moral values and are in touch with the value sciences — particularly moral and social philosophy, and religion — in their role of directing attention to questions of meaning, purpose and responsibility.

But the interaction is not, or should not be in one direction only. The value sciences themselves are in constant danger of becoming (or remaining) producers of idealistic pipedreams or privitistic religiosity, unless in touch with and applied to the concrete social context of human interaction, rights and duties, which is largely the province of law.²

So much for a brief justification of an ethics paper in a legal project. As for the particular subject, "sanctity of life, quality of life", it too requires little justification to prove that it is a fundamental issue and concern both in medical ethics and in medical law.

But while the sanctity of life principle is probably the single most basic and normative concept in ethics and in law, it is also one of the most elusive. There remains an incredible amount of variety and uncertainty about its meaning, origins and specific normative value. It long ago reached the "motherhood" stage in appeals and argumentation — never opposed, but seldom defined, and used for the emotional support of quite contrary causes.

That being the case, and inasmuch as the roots of the concept are in theology and Bible, and some of its branches in philosophy, it

would seem a useful exercise in a legal "protection of life" project to sort out and distinguish in this concept reason from rhetoric, uses from abuses, relevance from irrelevance.

Our point in doing so is not a purely academic one or one without serious policy implications for both morality and law. Insofar as there are those who reject "sanctity of life" as meaningless, some of whom wish to replace it or combine it with "quality of life" considerations, the sanctity of life principle is not only the subject of differing interpretations — its continued life expectancy itself may be in question.

But is it in reality? Are the two notions, sanctity of life, quality of life, really mutually exclusive? Need it come down to an either/or choice? As I will attempt to demonstrate, the notion of "quality of life" is itself elusive and varied in its meanings and usages; it is surrounded with about as much rhetoric and emotion as is "sanctity of life"; its many usages require careful sorting out and evaluation.

My major question is this: would morality (and therefore potentially law as well) have to abandon the commitment to the sanctity of life principle if it were to recognize the validity of some quality of life concerns, for instance by affirming that a biologically alive but brain dead body is a dead person; or by continuing to prohibit murder but explicitly allowing some forms of cessation of life support treatment for "quality of life" reasons?

At the moment such moves might appear to be possible only by an abandonment of our commitment to the sanctity of life. It is often maintained that our legal theory (as expressed for instance in the *Criminal Code*), on the basis of the absolute sanctity of life is essentially "vitalistic". That is (it is argued), it is primarily concerned with protecting human life itself, no matter how minimal the level, kind or condition (*i.e.* "quality") of the life in question, including those capable of being kept alive only by medical life supporting treatment.

It is true that in many situations (covered by tort law) in which life is only indirectly at risk, sanctity of life appears to be just one interest or value weighed along with a number of others in determining the extent of legal protections of life before the event, and of damages for loss of life or injury after the event. But in the medical arena, when decisions about life and death and the integrity of life are directly at issue, legal theory appears to consider sanctity

of life as not just *one* factor among others in determining prohibitions, responsibilities and sanctions — it is the conclusive and fundamental factor.

It is also true that there is a wide gap in this regard between legal theory and legal *practice* in the form of court decisions. In many “euthanasia” and cessation of medical treatment type cases for instance, courts tend to give a great deal of weight to circumstances, motives and other mitigating circumstances, and more often than for other cases either acquit or give very reduced sentences.³ But in such cases there is really no formal acknowledgment or recognition in legal theory of any validity to quality of life considerations. The acquittals or reduced sentences are often arrived at by circumventing that issue and basing the verdict on defences such as insanity.⁴ A remaining question then is, are there any compelling *moral* arguments based on the sanctity of life principle, as to whether the *Criminal Code* should or should not explicitly distinguish between and differently sanction (on the basis of quality of life factors), murder on the one hand and some other instances of killing or allowing to die in a medical context on the other hand?

It is worth noting here that even if there turn out to be no strong moral arguments against such a distinction, one cannot automatically conclude that the law in this regard should change. There could be reasons other than strictly moral ones to retain the law as it is. Many of those considerations are beyond the scope of this paper. As well, the appropriateness of the model of law in general in coping with issues of medical ethics, a question this paper will deal with in discussing rights, has at least some relevance to the pros and cons of such changes in the law.

As for the questions referred to earlier, it is time now to indicate in summary form this paper’s answer or thesis. For ethics, medicine, or law to acknowledge and articulate the validity and importance of quality of life concerns need imply in itself no threat to a commitment to the sanctity of life; it need not involve either making the sanctity of life a “relative” value or positing “exceptions” to the principle of the sanctity of life. On the contrary, to acknowledge and attend to quality of life factors (with the qualifications, protections and criteria to be proposed later in the paper) can in fact be a reasonable and necessary expression and defence of the sanctity of life principle itself.

It is in other words morally justifiable and even imperative for “quality of life” to stop being embarrassed, to “come out of the

closet" and claim the rights it merits. "Sanctity of life" need not feel threatened — there is plenty of moral elbow room for both perspectives. The crucial condition however for a happy and productive relationship between them is that they work out their "real identity" and be themselves. This paper will attempt to do just that and will conclude that sanctity of life need not mean, "vitalism", and quality of life need not mean, "relative worth". Once those pseudo personalities have been discarded, there need be no obstacles to their compatibility.

Lest my consideration of sanctity of life and quality of life be too abstract and wide ranging, the primary (though not exclusive) focus and application will be on the very concrete yet difficult issues of life saving or life supporting treatment decisions for terminally ill adults and defective newborns. Hopefully the moral principles and priorities applicable to that question are relevant to many other quality of life issues in medical ethics as well. Inasmuch as genetics issues raise some urgent questions in the context of sanctity of life/quality of life, I will in this paper draw examples from and make applications to the subjects of genetic engineering and genetic screening whenever possible.

On the other hand, quality of life decision making cannot adequately be considered in isolation from a number of related issues, implications and assumptions which could as well be treated from perspectives quite other than sanctity of life/quality of life. One such is the question of rights. But not to deal in this paper with rights issues would be to suggest that the "who controls", "who decides" question is not important for quality of life criteria and priorities. I believe it is.

An explanation and an apology to the reader might be in order here at the outset. It is possible that the paper's length and the large number of subjects and issues promised in the table of contents will lead one to expect a detailed and thorough analysis of all those topics. In large part such expectations will not be fulfilled. Obviously whole volumes and even libraries have been written on any one of those issues and the debates each engenders. Here they are included in a tailored and abbreviated manner to fit the single purpose of clarifying the central theme — sanctity of life and quality of life. I regret both those distortions and omissions which are inevitably a by-product of a survey paper, and any which may be due more to my own inaccurate analyses or ingrained bias.

This paper's particular theme and focus as well as its generally ethical orientation has also meant excluding or making only passing reference to many excellent works neither formally ethical in nature nor directly relevant to our subject. Yet inasmuch as some of them contain much wisdom, sensitivity and information on the subjects of life, death and dying, they are in my view essential reading for any one considering the subject or any others in this general area. Whether or not one agrees with all their analyses, the following are, in my view, among the most impressive: Ernest Becker, *The Denial of Death*⁵; Jacques Choron, *Death and Western Thought*⁶; Philippe Ariès, *Western Attitudes Toward Death*⁷; Ivan Illich, *Medical Nemesis*.⁸

I am grateful to many individuals and groups for their direct and indirect assistance in the preparation of this study. First among them is my long suffering and ever patient wife and in-house editor, Rachelle, to whom I dedicate this book with deepest affection.

Some of those who read early drafts and provided me with their comments and criticisms may not agree with and are not to be blamed for all my final analyses and proposals, but to all their challenging comments and criticisms goes much of the credit for whatever clarity and insight is to be found in these pages. Among those who merit my gratitude in this regard are especially my colleagues in the Protection of Life Project and other members of this Commission, particularly the following: Jean-Louis Baudouin, Janice Dillon, Marcia Rioux, Margaret Somerville, Gerry Ferguson, Edward Ryan, Marvin Goldman, M.D., Paul-André Meilleur, M.D., R. E. Turner, M.D., Harvey Yarosky, Jean Castel and Patrick Fitzgerald.

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Nor should I forget my students of the past two years in the Department of Law at Carleton University, upon whom I tried out much of what is contained in this book, but who helped me greatly in our discussion and seminars to shape and refine it.

And last, but not least, my thanks to the Commissioners and the Secretary of the Law Reform Commission of Canada for providing me with the opportunity and the time to undertake this study in the first place and for their encouragement while it was underway.

It is a question whether without restoring the category of the sacred, the category most thoroughly destroyed by the scientific enlightenment, we can have an ethics able to cope with the extreme powers which we possess today and constantly increase and are almost compelled to use.

— Hans Jonas

. . . our coming of age leads us to a true recognition of our situation before God. God would have us know that we must live as men who manage our lives without him . . .

— Dietrich Bonhoeffer

I cannot but have reverence for all that is called life. I cannot avoid compassion for all that is called life. That is the beginning and foundation of morality.

— Albert Schweitzer

So act in every case as to treat humanity, whether in your own person or in that of any other, as an end, and never as a means only.

— Emmanuel Kant

PART I

THE SANCTITY OF LIFE PRINCIPLE

Chapter 1

Roots of the Concept

It is rightly claimed that the starting point, the foundation for any formulation or reformulation of biomedical laws, codes or consensus should be the sanctity of life principle. That principle has, after all, been the one most fundamentally and continually appealed to in our western culture as the justification for moral rules, laws, human rights and social policies. But what does it really mean? How useful can it be in practice? Where does it come from?

It is claimed that the principle is still our best available source and focus of moral consensus. But is that true only at such a high level of abstraction that the principle becomes of little practical use when applied to specific moral problems? Is it only another "motherhood" principle? Even one of the strongest proponents of its continuing validity, the theologian/philosopher Daniel Callahan admits that "the principle is vague in its wording, erratically affirmed in practice, and open to innumerable differences in interpretation".⁹

And a philosopher who feels the principle needs to be dramatically "reconstructed" writes even more emphatically, "It is often said that 'human life is sacred'. This sentence is thought to express a 'sanctity of life principle', or SLP for short. That men actually talk this way, that they use the same speech or orthographic patterns, does not mean that they are all saying the same thing, or that the principle is simple. In fact the opposite is the case. The SLP is open to, and is often given, different interpretations. It is chameleon-like, changing its colours according to the moral theory it rests upon. It is almost as if a family of related but differing principles were hidden under the rubric of the SLP in order to give the impression of moral consensus."¹⁰

In fact relatively few studies in which the sanctity of life principle is at issue to one degree or another seem to acknowledge the element of ambiguity in the principle or to indicate and justify how the authors understand that principle. An example from the legal perspective is Glanville Williams' otherwise excellent book, *The Sanctity of Life and the Criminal Law*.¹¹ Nowhere does he indicate to the reader what he means by "sanctity of life".

To determine what the sanctity of life principle means and whether there is or can be any consensus and practical utility to the principle, the first step will be to briefly trace its roots.

A. The Roots in Theology

The sanctity of life principle clearly has religious origins, both in Eastern religions (especially Hinduism) and in the Judeo-Christian traditions. Inasmuch as Western law was shaped to a large degree by Judaism and Christianity¹² it is arguable that the centrality of the sanctity of life principle in law is largely religious in origin and orientation. Recalling here these now largely forgotten and seldom articulated religious links between religion and law, therefore seems appropriate in a paper directed to, among others, law makers and law reformers. Ideally we can best make rational choices about which values we choose to continue protecting in any new formulation of the sanctity of life principle only by recalling and articulating the religious and secular values and insights which shaped and shape that principle.

1. The Two Major Themes

Confining ourselves to recent and present day theologians and/or religious arguments we find a number of frequently recurring themes, and a general agreement between Protestant and Catholic analyses of the sanctity of life principle. There are two major and related "root" themes.

Man's dignity, worth and sanctity are from God, and not due to some quality or ability in man

Moral theologians and others who argue this theological point in our times base their views in large part on Karl Barth's theology of creation, redemption and "respect for life" (the latter expression being one Barth borrows from Albert Schweitzer). For Barth life is sacred and worthy of respect not because of something in life itself by itself, but because of what God has done, a God who is Himself holy. Barth puts it this way: "Life does not itself create this respect. The command of God creates respect for it. When man in faith in God's Word and promise realizes how God from eternity has maintained and loved him in his little life, and what he has done for him in time, in this knowledge of human life he is faced by a majestic, dignified and holy fact. In human life itself he meets something superior. He is thus summoned to respect because the living God has distinguished it in this way and taken it to Himself."¹³

The Protestant moral theologian Paul Ramsey makes the same point, and contrasts the religious position to the secular or modern one when he writes: "... in modern world views the sanctity of life can rest only on something inherent in man. . . . One grasps the religious outlook upon the sanctity of human life only if he sees that this life is asserted to be surrounded by sanctity that need not be in a man; that the most dignity a man ever possesses is a dignity that is alien to him. . . The value of a human life is ultimately grounded in the value God is placing on it. . . That sacredness is not composed by observable degrees of relative worth. A life's sanctity consists not in its worth to anybody. . . "¹⁴

Life is a gift in trust, it is on loan, man does not have dominion over it

This too is a theme which recurs constantly in both Protestant and Catholic analyses. An example is Norman St. John-Stevás, a

Catholic: "The value of human life for the Christians in the first century A.D., as today, rested not on its development of a superior sentience, but on the unique character of the union of body and soul, both defined for eternal life. . . Its other aspect is the emphasis on the creatureliness of man. Man is not absolutely master of his own life and body. He has no dominion over it, but holds it in trust for God's purposes."¹⁵

Paul Ramsey (a Protestant) puts it this way: "Every human being is a unique, unrepeatable opportunity to praise God. His life is entirely an ordination, a loan, and a stewardship."¹⁶

2. Some Difficulties

While there is substantial agreement among Protestant and Catholic analyses, largely of course because both analyses have roots in the same Judeo-Christian traditions, there are of course some differences as well. And the religious positions on the sanctity of life principle as sketched above are not without their difficulties or at least remaining questions. There are several worth noting here.

The first has to do with what theology proposes as one of the bases of the sanctity of life principle, namely the lordship and absolute sovereignty of God over human life and death. The difficulty or question which arises is why then a sovereign God who cares for human life — which He must if He holds human life as sacred — does not prevent or cure illness. Since He does not in fact appear to do so, one can only conclude that if He really is sovereign He does not in fact care, or He wants people to have at least some degree of control over human life, death and sickness.

The problem raised here of course is no less than the problem of evil, one which theology has grappled with for centuries. Getting too deeply into it would obviously take us too far afield. It is however a fact that (as I will note in greater detail below) a large part of Judeo-Christian theology has opted for the second of the two possibilities indicated above — that God shares with his people some decision making power in life and death matters. Not only theological treatises, but a considerable amount of Christian practice supports this conclusion — even in "Christian" states and times it was generally permitted to take another's life in defence of one's own, or to imprison and to execute those judged dangerous to society.

A second question has to do with whether one can in fact reconcile the religious view that man gets his worth and dignity entirely *from God*, with the secular modern view which sees man's sanctity and dignity as *inherent in man*, intrinsic to man. As Daniel Callahan observes, "in the theological problematic. . . it makes no sense to talk of man apart from his creator and redeemer; the 'natural man' does not exist, but only the created and redeemed man. . . In part this helps to solve the problem of an 'alien dignity' which would denigrate man's intrinsic worth, but at the same time, it requires that we accept the full theological framework; that is just what many cannot do".¹⁷

This brings us to a third difficulty with the religious explication of the sanctity of life principle — it is appropriate and convincing only to those who accept the religious viewpoint, who are believers. And since a large number of people are not or never were religious, that basis alone for the sanctity of life principle is hardly likely to be one around which a consensus can be identified or built.

But just before moving on and looking for another, more secular basis, let us at least attempt to distil some conclusions from the theological roots of the sanctity of life principle, putting aside the particular tenets of faith which nurture those roots. In doing so we might in part find that, though the arguments advanced by the theological and secular perspectives differ, there is at least a roughly equivalent investment in the centrality and meaning of the principle. One could say that the religious roots I have sketched can be distilled into these three statements:

- (i) The sanctity of human life is not the result of the "worth" a human being may attribute to it — either to one's own life or that of others. Considerations such as "degrees of relative worth", "functional proficiency", or "pragmatic utility" which humans may acquire or have are in no sense appropriate yardsticks for determining or measuring sanctity of life.
- (ii) Human life may not be taken without adequate justification, nor may human nature be radically changed.¹⁸
- (iii) The sanctity of life principle is basic to our society, and its rejection would endanger all human life.¹⁹

B. The Roots in Experience and Intuition

The roots of the sanctity of life principle are clearly religious. But not even theologians normally claim that theology is the only basis of important moral principles. In this regard one could hardly do better than cite the observations of the theologian James Gustafson. While acknowledging that theology is significant to believers, he adds, "For most persons involved in medical care and practice the contribution of theology is likely to be of minimal importance, for the moral principles and values can be justified without reference to God, and the attitudes that religious beliefs ground can be grounded in other ways. . . Functional equivalents of theology are present in the patterns of actions and the ethical thought of persons who find theology to be a meaningless intellectual enterprise."²⁰

Gustafson is no doubt correct in general but at least on the subject of the sanctity of life principle not many of those "functional equivalents of theology" have in fact been articulated and argued in any detail. One of the few such efforts is that of Edward Shils.²¹

1. Roots of the Principle in the Nature of Things

Shils builds his position on the "common experience" of mankind. Despite waning theological belief, many of the actual or prospective interventions of biomedicine give rise to a "deep abhorrence or revulsion". Why is this? Not just because those who are no longer believers are still unconsciously motivated by vestigial traces of religious belief. On the contrary, "The source of the revulsion or apprehension is deeper than the culture of Christianity and its doctrine of the soul. Indeed, it might be said that the Christian doctrine was enabled to maintain its long prosperity and to become effective because it was able to conform for so many centuries to a deeper protoreligious 'natural metaphysic'."²²

There we have it. Both for those who are and are not religious the experience of a deep respect for human life (as recognized for instance in law by the *Bill of Rights*) can be traced ultimately to the nature of things, to the way things are — a protoreligious, natural metaphysic. He goes on to say,

The chief feature of the protoreligious 'natural metaphysic' is the affirmation that life *is* sacred. It is believed to be sacred not because it

is a manifestation of a transcendent creator from whom life comes: it is believed to be sacred because it is life. The idea of sacredness is generated by the primordial experience of being alive, of experiencing the elemental sensation of vitality and the elemental fear of its extinction. Man stands in awe before his own vitality, the vitality of his lineage and of his species. The sense of awe is the attribution and therefore the acknowledgment of sanctity. All else man feels to be sacred derives its sanctity because it controls or embodies that sacred vitality of the individual, the lineage and the species.²³

Though he does not use the expression "sanctity of life", P. D. Medawar's writing on the subject of genetic options makes much the same point when he writes: "At what point shall we say we are wantonly interfering with nature and prolonging life beyond what is proper and humane? In practice the answer we give is founded not upon abstract moralizing but upon a certain natural sense of the fitness of things, a feeling that is shared by most kind and reasonable people even if we cannot define it in philosophically defensible or legally accountable terms."²⁴

There is nothing in Shils of the "alien dignity" version of sanctity proposed by the theological perspective we noted above. Quite the contrary. For Shils, as for the "secular" perspective in general, dignity, worth and sanctity are inherent in men, grounded in the way things are, not given and maintained by God. Nevertheless it is worthy of note that when it comes to the "bottom line" the religious and secular views may not be so far apart.

Barth and Shils are both able, from their quite different perspectives to speak about our "standing in awe" before human life. Shils wrote (above) that "man stands in awe before his own vitality". Barth wrote that, "Respect [for life] is man's astonishment, humility and awe at a fact in which he meets something superior — majesty, dignity, holiness, a mystery which compels him to withdraw and keep his distance, to handle it modestly, circumspectly and carefully."²⁵

And Shils is very close to the view we noted above of St. John Stevas, when he writes that if sanctity of life goes, "... then nothing else would be sacred."²⁶

It may not however be entirely correct to characterize the "secular" perspective, as opposed to the "religious" perspective; as one which always sees sanctity as inherent in man, intrinsic to man. For instance, Danner Clouser, though he has serious reservations about the usefulness of the concept, (see below), yet acknowledges

that sanctity could be seen as at least a "derived" property of life given the prior acceptance of religious propositions such as creation. But, he argues, apart from the religious context, "There is no universally accepted theory — if at all — that entails a property called 'sanctity'." He therefore concludes that sanctity of life "is more something we pledge ourselves to, a commitment, than it is an objective property that demands acknowledgment".²⁷

2. Some Problems and Questions

As with the theological explication of sanctity of life, so with the philosophical or secular, there remain problems and questions. As Shils himself admits, not everyone in fact acknowledges, certainly not in their practices, that life is valuable or "sacred". Man's indifference to and destructiveness of the lives of his fellowman is, after all, evident and continuing. But Shils counters that, "Its [life's] sacredness is the most primordial of experiences, and the fact that many human beings act contrarily, or do not apprehend it, does not impugn the sacredness of life. . . The fact that many human beings often act irrationally does not deny the value of reason."²⁸

One is inclined to agree, yet disagree. Certainly, as Shils notes there does seem to be a widespread intuition that life is valuable and inviolable, despite the exceptions and the "gradations" of sanctity we all too readily grant in our dealings with others. But if the sanctity, the inviolability of human life is truly "the most primordial of experiences", to completely prove that this is so one would have to establish that everyone at all times experienced human life as inviolable. By his own admission this does not seem possible. That kind of evidence is not available, whereas exceptions to his global claim are more than plentiful.

A further objection might be that simply experiencing something is not in itself proof of its worth, its value. One could be wrong; one could decide later after time to evaluate and weigh the experience, that one was wrong. Nor does the mere experience of something, even if it is common and universal, imply and impose an evident moral duty or series of duties. In this regard the believer is in a better position, possessing as he does an ethical framework, an extrinsic norm with which to evaluate experience and determine his duties. But of course the non-believer would see a weakness in the believer's need to rely on something outside human life (*i.e.* "revelation") for that framework.

Similar difficulties of proof and evaluation are involved in the related moral view and argument based on Kant's thesis that persons are ends in themselves, not means. That being the case, it is argued, to take the life of persons or interfere with the freedom of persons is morally reprehensible.

The first difficulty from the philosophical perspective is that of supplying proof that in fact persons are ends in themselves, that rational beings have an absolute value. As noted above, intuition or experience alone does not constitute proof of value or determine moral duties.

But more importantly, and this is a point I will come back to later, there is a tendency in the various versions of this view to assume too much in the assertion that *persons* or rational beings are ends in themselves or have absolute value, even if that is granted. To assume that their *lives* are equally absolute (which is why it is claimed they cannot be killed) does not really follow. As one commentator puts it, "Only by a confusion between a *rational being* on the one hand and its *life* on the other could we conclude from the fact that the former is an end in itself that the latter has absolute value as well — without any qualifying consideration. It is entirely compatible with the thesis of rational beings as ends in themselves that only a certain quality of life is deemed livable for them, and that in the eventuality of its non-realization, the life of that being ought to be terminated."²⁹ [Emphasis added]

C. Conclusions: Some Agreements

So much for the roots of the principle in theology and experience. There remain and will remain vast differences between the two perspectives. We have indicated some of them. No one has yet managed to satisfactorily reconcile the two approaches in theory. But there are also agreements, and I have indicated some of them as well. The most important point of practical agreement, of practical consensus, is of course in the affirmation of the principle itself, at least in its general lines and orientation, as the fundamental one and the starting point for all biomedical decision making. That in itself is no small matter. We are thus able to say that, "... the concept is an expression of a basic intuition about human life that can be had

by men who are not religious in the narrow sense of the term. . . the intuition that gives rise to the concept of the sanctity of life is somehow related, in an intrinsic and positive way, to the mystery that overhangs all finite existence. Religious concepts and myths specify the nature of this mystery, but such specification is not necessary to recognize its existence and the fact that it must be taken into account somehow (at least in terms of reverence, caution and humility) when we deal with persons.''³⁰

One does not want to suggest that everyone accepts the principle, or applies it in the same way. Neither is the case as we shall see below. But it or some equivalent principle is widely affirmed, implicitly or explicitly. Commentators tend to agree that the principle includes at least these three points:

- (i) Human life is precious, even mysterious, and is worthy of respect and protection. Human worth is not determined merely by subjective or utilitarian concerns.
- (ii) Human life may not be taken without adequate justification, and human nature may not be radically changed.
- (iii) The sanctity of life principle (or an equivalent principle) is basic to our society and its rejection would endanger all human life.

Chapter 2

Meaning and Use of the Concept. The Options

When it comes to what the principle means more specifically, how it is used in practice in biomedical issues, agreement and consensus are more elusive. In terms of articulated and working options or "thrusts" which explicitly or implicitly refer to the principle, there are probably three major ones. Proponents of each of course claim to be fully and uniquely faithful to what the sanctity of life principle "really" means, even those who feel the concept is more or less useless for practical purposes. I will attempt to sketch the three options and weigh the pros, cons and implications of the arguments advanced for each. (My own choice will be the third option). The three are:

1. "Vitalism" is the (only) valid expression of the sanctity of life principle. In this view the sanctity of life principle therefore excludes and is opposed to quality of life concerns; or
2. The sanctity of life principle is false or meaningless, and in need of replacement or reconstruction; or
3. The sanctity of life principle tests and finds its content in rules and rule systems, including rules which focus on quality of life factors.

A. "Vitalism"— the (only) Valid Expression of the Sanctity of Life Principle?

By medical vitalism in the context of preservation of life issues I mean an approach which insists that where there is human life, even mere metabolism and vital processes, no matter what the patient's

(or newborn's) condition, or the patient's wishes, it would be inconsistent with the sanctity of life principle either to cease to preserve it or to interfere with it.

Applied to genetic counselling (and the consequent options to procreate, avoid procreation, continue a pregnancy, or abort a defective foetus), as well as genetic research and engineering, a vitalistic interpretation of sanctity of life goes in the same direction.

Used in these genetic issues, it would typically insist on the following points:

- parents don't have the right to abort a genetically defective foetus;
- parents, physicians and society are not free to choose the genetic quality of children;
- the interests of both individuals and community are best served by continuing the pregnancy and preserving the new born life of genetically (or otherwise) defective children, no matter how damaged or high the costs of preserving that life;
- because life is sacred scientists have no right to intervene in the natural processes of human life by means of genetic research and engineering;
- to encourage such research and manipulation is to risk qualitative changes in human life and the values we attach to life;
- it risks, in human hands, a dangerous and unpredictable control over human nature and destiny which ought to be left to God and/or the laws of nature.

It remains true of course that some (or all) of these views could also be held on grounds other than "vitalism". It is equally true that "vitalism" is more a predominant attitude than a "school" professing a single body of tenets.

In this view then, wherever there is human life, any human life, whether comatose life, foetal life, deformed or suffering life, the sanctity of life principle is the final, conclusive reason against taking, ceasing to preserve or (genetically) altering it. The principle is not one reason to weigh along with others — it is the only one that counts. Nor does the principle in this view admit of a need for any further qualifications or exceptions. It is to be applied as it is and

equally to all issues in which human life is in danger of being taken, not preserved or altered. It settles decisions about abortion as readily and directly as decisions about the comatose.

1. Sanctity of Life and Quality of Life Irreconcilably Opposed

This option therefore sees the sanctity of life principle and quality of life concerns as opposed and irreconcilable. Its proponents assume that if one allows quality of life factors to enter into medical decision making, even as one of several things weighed, one is partially or totally rejecting the sanctity of life principle.

This assumption can even find its way into supposedly value neutral opinion surveys. A recent example is a survey of physicians, nurses, and medical, nursing and college students on attitudes toward euthanasia. Though the questions dealt with both "active" and "passive" euthanasia, as well as a number of ambiguous attitudinal implications and conditions, the report of the survey describes the weighting of the questions this way, "Weights were assigned to statements so that responses indicative of a favourable attitude toward euthanasia were assigned a low score, *i.e.*, a weighting of 1 or 2, while attitudes favourable to the 'sanctity of life principle' were assigned a score of 4 or 5".³¹

Given the ambiguity of the term "euthanasia", which can mean killing or allowing to die, it is at least simplistic to suggest that it is always opposed to sanctity of life.

It is equally assumed (in this view) that "quality of life thinking" must necessarily involve value judgments about the "worth", "usefulness", or "meaningfulness" of the lives under consideration and that these judgments necessarily imply a *comparison* of the relative worth, utility and meaning of different lives. An example is this view by a professor of Talmudic law: "... human life is of infinite value. This in turn means that a piece of infinity is also infinity and a person who has but a few moments to live is no less of value than a person who has 60 years to live... a handicapped individual is a perfect specimen when viewed in an ethical context. The value is an absolute value. It is not relative to life expectancy, to state of health, or to usefulness to society."³²

The same point is put even more forcefully by Jean Rostand. "For my part I believe that there is no life so degraded, debased,

deteriorated or impoverished that it does not deserve respect and is not worth defending with zeal and conviction. . . ."³³

"Vitalists" are generally suspicious of the motives of those who wish to include quality of life concerns in medical and research decision making, no matter what conditions, safeguards or guidelines might be proposed at the same time. It is assumed that at worst "the qualifiers" have devious and hidden motives, or at best that whatever they intend, the results will be an opening of the floodgates to an ever decreasing respect for human life, a substitution of subjective and shifting values and tastes for an absolute unchanging norm. As one writer typically expresses these fears, "The expression 'quality of life' is the latest rhetorical ploy to seduce people into abandoning their moral obligations to those who are in extreme need of human love. What they really want, once their socially respectable mask is removed is more latitude for direct killing."³⁴

Another commentator expressed similar fears when he said, "The real quality of human life is in its very existence, which is given to it by God himself, and not by the practical performance and the effectiveness of it, which seems to me to reflect the modern attitude that only results matter. Our success-oriented society is beginning not to care about people."³⁵

2. Wedge Arguments and Historical Precedence

What the above and similar views also are expressing to one degree or another is the "slippery slope", "wedge" or "foot-in-the-door" argument. The argument is that once some form of killing, letting die or altering of human life is legitimated in a particular instance, though it may be compassionate, sometimes morally justifiable or at worst a minor evil in itself, if allowed and applied generally it will, despite goodwill and the best available safeguards, lead to wrongs of ever increasing magnitude. Therefore it is best not to take that first step, not to put that first wedge or foot in the door. A warning clearly expressed in this form is that of Jean Rostand.

Above all I believe that a terrible precedent would be established if we agreed that a life could be allowed to end because it is not worth preserving since the notion of biological worthiness, even if carefully circumscribed at first would soon become broader and less precise. After eliminating what was no longer human, the next step would be to eliminate what was not sufficiently human, and finally nothing would be spared except what fitted a certain ideal concept of humanity.³⁶

Yet another related plank in the vitalist platform (though by no means restricted only to that platform) is the argument from historical precedence. The argument is that a glance at history, particularly recent history in the form of the Nazi medical/experimental atrocities, makes the slippery slope argument all the more compelling. After all, under the Nazi regime euthanasia and experimentation may have begun with "humane" intentions, and may not have been initially racist.³⁷ But gradually, step by inevitable step, voluntary euthanasia for the terminally ill evolved into involuntary euthanasia imposed upon anyone determined to be useless to society or an enemy of the state, including the mentally retarded and especially Jews. Genetic and other research on consenting human subjects which may have begun for therapeutic reasons finally became experiments on non-consenting subjects who became simply expendable means for the advancement of medical science.

Hard evidence of the resulting devaluation of human life in the Nazi era is of course available, and must never be forgotten. For instance these excerpts of letters from the I.G. Farben Chemical Trust to the Auschwitz concentration camp:

In contemplation of experiments with a new soporific drug, we would appreciate your procuring for us a number of women. . . We received your answer but consider the price of 200 marks a woman excessive. We propose to pay not more than 170 marks a head. If agreeable we will take possession of the women. We need approximately 150. . . Received the order of 150 women. Despite their emaciated condition they were found satisfactory. . . The tests were made. All subjects died. We shall contact you shortly on the subject of a new load.³⁸

3. The "Playing God" Argument

Yet another formulation of the "vitalist" option is the argument that to take human life, to not preserve it or otherwise to intervene in the "natural processes" as long as life persists, even if only at the biological vital processes level, is a form of "playing God". This argument can of course be compelling both to those who accept the religious foundations on which it rests and to those who object to "playing God" whether or not God exists. As regards euthanasia the argument is formulated this way, "The prerogative of giving life belongs to God; nor may that prerogative be usurped. Conversely the prerogative of taking life. It is God's and God's alone. In his wisdom he has decided who should live and who should not; who should die and when. . . Consequently euthanasia as a preternatural

hastening of the appointed time of death, constitutes an unacceptable interference in the work of God."³⁹

In the context of genetic issues, the "playing God" argument against interference tends to be formulated similarly: "Man is made in the image of God, and to alter the fundamental image of man is to 'play God' which is not only religious idolatry but also a movement beyond the healthy recognition of human finitude that keeps various forms of evil in check."⁴⁰ One should not of course assume that such "playing God" arguments are used only by vitalists. They are also used by those who accept the validity of quality of life concerns — but in the latter case the argument is used against those judged to be too wide in their understanding of quality of life, or too lax in the criteria used in decision making.

4. Optimism About Life

There is a final, more global argument which lies behind and fuels much of the vitalist interpretation's tenacity and appeal. The argument begins by identifying in our great preoccupation with limiting, ending and modifying human life a common, dominant and regrettable theme running through all the biomedical issues. The theme (it is argued) takes a number of related forms: a pessimism about human life; a preoccupation with death; a sanctifying of death, but not life; a strong suggestion that life is not really worth living. The argument then continues by countering this pessimism (and the consequent attempt to end or reshape human life) with the positive, and optimistic rejoinder that because life is "sacred", it is good and worth living.

What is argued is not that there are no problems and evils in human life which need correcting, medically, socially and otherwise. They are usually admitted. The target of this argument, this observation, is largely the "preoccupation" with the defective side of human life and the consequent "compulsion" to prevent it, end it or remake it. Abraham Kaplan expresses it this way:

What are the problems of medical ethics with which we have been occupied? It seems to me that we can identify them in a very simple way. They are those we would be coping with if we lived in a society which somehow feels that life is at best only a necessary evil. First is the problem of contraception — how to prevent life from coming into existence at all. If we do not succeed in that, we face the problem of abortion — how to destroy it once it has begun. Next we move to the problem of 'genetic engineering'... how to reshape it in our own image, for apparently it is not quite acceptable as it is. If we are not

capable of modifying life, we have at any rate the problem of medical experimentation — how we can best learn what can be done with it. And if all else fails, we come finally to the problem of euthanasia — how we can put an end to life which we have been powerless to prevent or improve upon. . . there is an irony in the fact. . . that our deliberations on the sanctity of life take place against the background of a deep and widespread preoccupation with death that is characteristic of our culture.⁴¹

A recent editorial on the subject of contraceptive research began in a similar vein: "God may have created man in his own image. But man is not in every way pleased with the handiwork of his maker. And cantankerous revisionist that he is, man sets out to modify the merchandise, sometimes intentionally, sometimes not, sometimes in fundamental ways, sometimes with horrific results (remember thalidomide)."⁴²

I shall wait until the discussion of the "third option" to examine, reply to (and even in some respects agree with) the arguments and assumptions contained in this first option, sanctity of life as vitalism, and now briefly sketch a second manner in which the sanctity of life principle is treated.

B. The Sanctity of Life Principle — False or Meaningless?

The first option just discussed claims that the sanctity of life principle provides "the" answer, in a final absolute manner to questions about ending and modifying life. No other principle or qualification of the sanctity of life principle is required. Human life at any level must be preserved. Quality of life and sanctity of life are opposed and mutually exclusive, and in any contest between them in medical decision making, sanctity of life must always be the winner. But a significant number of commentators strenuously disagree.

Some agree that sanctity of life and quality of life are mutually exclusive, but argue that *quality of life* and not sanctity of life should win the day because sanctity of life necessarily means vitalism, vitalism is false, and so therefore is sanctity of life. A typical proponent of this view is Joseph Fletcher.

Others argue that sanctity of life is more or less meaningless as a concept and for practical purposes at least it should be replaced by moral rules such as "don't kill" or the love principle, or the rule of benevolence. K. Danner Clouser, for instance, advocates the moral rule "don't kill", and Marvin Kohl offers the principle of love or the rule of benevolence as worthy competitors for the sanctity of life principle.

1. Sanctity of Life Is Vitalism, therefore False

One should first of all attempt to identify the strands of Joseph Fletcher's argument that the sanctity of life principle is false and ought to be replaced by a quality of life ethic. Fletcher first of all rejects vitalism. But that rejection is part of a larger issue for Fletcher, namely the precedence of needs over rights: "I believe that needs have precedence over rights; that is my ethical stance. Therefore to be candid and careful about this subject, I am not primarily concerned about any supposed right to live or supposed right to die, I am primarily concerned with human *need* — both of life and of death. That is my confession."⁴³

Fletcher then continues by equating vitalism with the rights approach in medical decision making and therefore rejects it. "As in the balance of rights and needs, needs should come first, so in the balance of biological life and human life, being a man or a person is of more value than simply being alive."⁴⁴

He then concludes on the same page that, "The logic of what I am saying is that we should drop the classical sanctity of life ethic and embrace a quality of life ethic instead." Fletcher in other words assumes and nowhere even attempts to argue this part of his case, that there really is only one possible meaning of the sanctity of life principle, *i.e.* vitalism, and that (therefore) it is opposed to a "quality of life ethic". It seems not to occur to him that there might be another, non-vitalist, interpretation of the sanctity of life principle, one which may not in fact be opposed to carefully formulated quality of life concerns and criteria. But more on that later.

Fletcher may be right when he implies that equating sanctity of life with vitalism is "the popular idea", but he himself appears to accept it without question. Whether that is "the popular idea" or not, I will take issue with him below on his further point, namely that, "... to say that biological life is not sacrosanct and that there

are more valuable things than being alive is to make a break with established religion and medical piety. . . in the realm of medical care the sanctity of life has had priority at all costs".⁴⁵ Not necessarily. As I will indicate below, the essential ingredients for a respectable argument establishing that biological life is not always "sacrosanct", and that quality of life concerns can express and protect a commitment to sanctity of life, can be found (among other places) in established religion and medical piety.

2. Sanctity of Life Meaningless, therefore Should Be Replaced by Rules

There are those, like Fletcher, who think the sanctity of life principle is false. But others argue that while it and "quality of life" may not be mutually exclusive, the sanctity of life principle (while perhaps not false), is more or less meaningless and in need of replacement when it comes to practical decision making.

K. Danner Clouser for instance feels that the sanctity of life concept is too vague and its implications too uncertain for it to be of much help in any formal way in ethics. He grants that it suggests the feeling of a deep sense of mystery about life, but observes that, "neither command nor obligation follows from the fact that we feel a certain way about life."⁴⁶

On the other hand synonyms such as "value of life" or "importance of life" seem weaker than "sanctity", suggest that life is less inviolable and sound subjective. He grants that he has some sympathy with a possible meaning or use of the concept as meaning not something exact which settles issues, but a general orientation toward life. "It is consistent with a point I think important, that 'sanctity of life' is more something we pledge ourselves to, a commitment, than it is an objective property that demands acknowledgment." But yet he goes on to say (on the same page) that, "... as it stands it seems impossibly vague. It involves believing life has value, that it should be treated as important, that it should be preserved — all other things being equal. But given this interpretation, it is not at all clear who would disagree. Is it even a helpful distinction? Does it separate anyone from anyone else? Wouldn't everyone — save wanton, whimsical killers — subscribe to this world view? . . . Surely nearly everyone agrees that life should be protected and not taken without a reason. . ."

Clouser concludes that the heart of the "world view" suggested by the concept is the "urging and practicing that life not be taken without adequate reason."⁴⁷ But since the concept leaves undetermined the crucial question as to when exactly taking life *is* justified, what it really seems to be saying (he argues) could be more directly and helpfully stated as the moral rule "don't kill".

Putting it this way (he argues) puts the focus on the real issue, that is, what will be the justified exceptions, since it is now formulated as a general prohibition to which there can be exceptions. To say "treat life as sanctified" (says Clouser) is simply not as clear and to the point as "do not take a life". Clouser himself puts it this way, "Being told the first, it would never be clear where and if you transgressed it. Whatever you did — as long as you were remembering that life was precious — you might feel you were treating life as sacred. But under the admonition, 'do not take life' anytime you were about to help die, let die, or turn off the respirator, you would immediately be forced to the real issue — what justifies it in this case? . . . Proclaiming 'sanctity of life' can keep one from ever directly facing up to these hard questions."⁴⁸

One is inclined to agree with Clouser that the concept by itself cannot answer the hard questions — what reasons count as justification for taking life, and what is and is not human life? Something else is needed by way of moral rules. But one need not agree with Clouser that those moral rules need to be or should be conceived as "exceptions" to the sanctity of life principle, rather than extensions or applications consistent with and supportive of the principle itself. Clouser has not to my mind proven that part of his case. That being so there is no necessity to choose between the sanctity of life principle and the moral rule he proposes. As I will attempt to establish below, they are equally important but for different purposes. The two propositions, "life is sacred", and "do not kill", are, after all, two very different propositions.

I do not agree that the richness and full significance of the sanctity of life concept can be boiled down to any single moral rule, and certainly not the one proposed. It seems rather that there must be many moral rules, enough to deal with all the biomedical issues to which that principle or concept can potentially extend. Decisions between life and death comprise one set of issues but they are not the only ones. Therefore if Clouser seeks a moral rule which can be of practical help in concrete decision making, the moral rule "don't kill" cannot possibly carry the load alone.

Clouser himself has some reservations on this score. One of those reservations concerns our obligations to future generations. He acknowledges that the moral rule "don't kill" does not really speak to that obligation, whereas the sanctity of life principle might. At this point we are inclined to say that yes, it does, but that particular obligation to future generations, like other obligations, also requires particular moral rules to express and apply the principle.

While some seek to replace sanctity of life with a *quality of life ethic* (i.e. Fletcher) and others with the moral rule, *don't kill* (i.e. Clouser), still others argue for substitutes such as the *love* principle or the rule of *benevolence*. Marvin Kohl for instance seeks to match them, particularly the latter, against the sanctity of life principle. For Kohl, as for Clouser, a sanctity of life principle which simply affirms that human life is sacred is too vague and flexible.

What Kohl claims to be doing is "reformulating", not discarding the sanctity of life principle. "My proposal is that the sanctity of life principle be reformulated."⁴⁹ But in effect he achieves his reformulation by entirely excluding euthanasia (more exactly "beneficent" euthanasia) from the umbrella of the sanctity of life principle. For he continues, "First it (the sanctity of life principle) should be interpreted as a rule, a rule which would not apply to cases of beneficent euthanasia." He appears in other words to consider (beneficent) euthanasia, not as an act for which one can or need argue justifying reasons consistent with the sanctity of life principle, but rather as an *exception* to the principle, as outside its reach, and regulated by another and competing principle, that of benevolence.

The reformulated sanctity of life principle ("one ought not to kill a human being whose existence or actions neither have caused nor will cause imminent harm") is thus presumably left to regulate other matters, but not euthanasia. Kohl then goes on later in the book to propose definitions, rules and paradigms for beneficent euthanasia, all of them as expressions of benevolence and the *prima facie* obligation that we ought to be kind when possible and to help those in need.

Euthanasia is defined as "the painless inducement of quick death," and the conditions or criteria for beneficent euthanasia are, "that the act must involve a painless inducement of quick death; that the act must result in beneficial treatment for the intended recipient, no other considerations are relevant."⁵⁰ He then proposes "paradigms" of beneficent euthanasia, focused on a number of

clearly "quality of life" concerns — among them, terminal and irremediable illness and excruciating pain, severely defective newborns, and so forth.

Leaving aside for the moment the pros and cons of beneficent euthanasia and the criteria and paradigms as proposed by Kohl, one cannot but agree (as I did with those already discussed) that a number of moral rules are in fact necessary when it comes to resolving moral problems and conflicts about concrete biomedical issues. But neither the other commentators nor Kohl have established that these rules (whether benevolence or any other) and quality of life concerns must necessarily or ideally replace, compete with or be exceptions to, rather than supplement, apply and express the sanctity of life principle.

Admittedly that principle is somewhat vague and undetermined, but neither common sense nor strict logic suggest any compelling reason why kindness, benevolence and quality of life factors (carefully delineated and with effective safeguards of course) are in any sense in competition with or exceptions to respect for human life. Common sense and logic, as well as the religious/experiential roots of the sanctity of life principle, suggest the opposite as I will now attempt to demonstrate.

C. The Sanctity of Life Principle—Fundamental and Meaningful?

The whole of this section will attempt to establish what the earlier sections challenged, that is, that the sanctity of life principle is not "vitalism", that it is fundamental and meaningful in biomedical decision making, and that it should include consideration of quality of life factors.

1. The "Theology of the World" vs. Vitalism

As already noted, it is argued or assumed by many, both those who support and those who oppose vitalism, that vitalism is entirely or largely consistent with the sanctity of life principle and is substantially what that principle promotes. It is in other words maintained that there can be no justifying reasons for the taking,

ceasing to support or interfering with human life even if reduced to only the biological processes, and that the application of the sanctity of life principle so understood is a *final and conclusive* criterion, admitting no qualifications or exceptions.

But is that really what the sanctity of life principle means? As indicated earlier, it is the thesis of this paper that any identification of vitalism with the sanctity of life concept is erroneous and unsupported by a careful reading of both the religious and experiential/philosophical roots of the concept.

It is quite true that the religious roots of the concept emphatically insist that human life ultimately comes from God, that God is ultimately the source of its worth and dignity, and that man does not have dominion over it. But do not the same religious roots and perspectives also affirm that God has "deputized" to man some of this dominion, some of this control over life? Does not the theological notion of life held "in trust" or "on loan" by man include a degree of responsible decision making by man, even in matters of life and death? Does not the biblical/theological understanding of the world, creation and life being "entrusted" to man, mean that he is responsible, a decision-maker, a transformer, a builder — all of this in response to God's command and with respect for the sanctity of life? While not all theologies or theologians would give an affirmative answer to those questions, many respectable theologies and a great deal of religious practice would.

First of all, religious practice. Judeo-Christian morality and practice have long affirmed that there is no inherent contradiction between acknowledging God's dominion over life and death, and yet acknowledging that individuals or the state may, in self defence, take the lives of those judged to be unjust aggressors or threats to the common good. Searches of the Bible and tradition appeared to legitimize for them the principle of a degree of control over life shared by God with man. And there is no evidence that killing in self-defence in response to a perceived threat was seen as an "exception" to God's dominion over life, or as a "qualifying" of the sanctity of life principle.

On the contrary, the arguments in favour of such killing in self-defence generally were (and are) to the effect that it is only legitimate *because* life is sacred and worthy of respect — particularly of course the lives of those unjustly threatened. My object here is not to determine whether killing in self-defence is, or is not, morally justifiable or whether it is applicable to biomedical issues. It

is of course a rationale often advanced in favour of abortion — *i.e.* that the foetus for one reason or another is an “unjust aggressor” threatening the physical or psychological well-being, rights or life of the mother. In my view the “unjust aggressor” argument applied to abortion or euthanasia is misplaced and unconvincing. But my point here is only that there are Judeo-Christian historical precedents (in contexts other than the medical) in which it was, and is, thought consistent with the sanctity of life to allow life to be taken and even to take life.

But we can and should go deeper. The “vitalistic” interpretations of sanctity of life, to the extent that they reject human control over human biological processes and matters of life and death, are denying to a greater or lesser degree man’s shared dominion over creation. And the groundwork for a refutation of that interpretation can be found in a number of influential and related theologies of recent years. Not in the more “fundamentalist” theologies, but in the “theology of the world”, the “theology of hope”, and “secular theology”. There is no single theologian who fully articulates all the themes these theologies represent, and there are different accents in the various treatments of similar themes (though one “accent” common to most is that of German!). Nor are all their analyses of the same weight, or without controversy, or equally compelling.⁵¹

But there are a number of important common denominators to be found therein relevant to our point that it is up to man, allowed to man and even sometimes demanded of man to intervene in the biological processes, and sometimes to stop supporting life itself. The starting point of these theologies is the Bible, and in particular texts such as Genesis 1:28 in which God says to man, “. . . fulfill the earth and subdue it; and have dominion over the fish of the sea and over the birds of the air and over every living thing that moves upon the earth. . . .”

There are of course other biblical texts which, if taken too literally encourage a “let God do it” attitude, and seem to give hardly any recognition to the existence of secondary causes and man’s right and responsibility to respect and control them. Among the many examples of such biblical texts is Psalm 147 which refers to a God who “covers the heavens with clouds, prepares the rain for the earth, makes grass grow upon the hills. . . .”

While continuing to affirm God as creator and lord, the “theology of the world”, underlines an equally valid and complementary affirmation — the autonomy of man. The “father” of

this theological perspective, the late Protestant theologian Dietrich Bonhoeffer, puts it this way: "... our coming of age leads us to a true recognition of our situation before God. God would have us know that we must live as men who manage our lives without him. . . The God who lets us live in the world without the working hypothesis of God is the God before whom we stand continually. Before God and with God we live without God."⁵²

It would take us too far afield to attempt a detailed exegesis or criticism of that statement by Bonhoeffer, but his central point is clear — God is ultimate cause, and continues to exist and be present to man, but he does not intervene to make our decisions for us. A less "radical" Catholic statement of the same point is found in one of the documents of the Second Vatican Council:

If by the autonomy of earthly affairs we mean that created things and societies themselves enjoy their own laws and values which must be gradually deciphered, put to use and regulated by man, then it is entirely right to demand that autonomy. This is not merely required by modern man, but harmonizes also with the will of the Creator. For by the very circumstances of their having been created, all things are endowed with their own stability, truth, goodness, proper laws and order. Man must respect these as he isolates them by the appropriate methods of the individual sciences or arts.⁵³

From the perspective of these theologies, the growing secularity and "hominization" or anthropocentrism of the world need not be seen as a threat to God's dominion or as a rejection of religious belief. Quite the contrary, it is in accordance with God's plan and a challenge to humans to take responsibility for the world. The theological world view which identifies this challenge, sees our times (in the words of Johannes Metz) as that of, "the transition from a divinized to a hominized world."⁵⁴ This theology does not pretend that there ever was a completely divinized world or that there will ever be a completely hominized world. We are to some extent, and always will be, in transition.

In the earlier more "divinized" world, the order of nature was seen as closed and menacing, absolutely superior to humans and accepted without question. Man was carried along, and whatever "shaping" of the world's civilization he accomplished, was restricted to a carefully defined and small corner, always surrounded by a larger, inaccessible and often overpowering nature. In that world religious faith and responsibility tended to involve a degree of flight from the world, a preoccupation with matters above and beyond human history and "unconquerable nature".

Powerful and uncontrollable nature, "seemed to possess almost divine features. . . It was ultimately also an excellent medium for his religious experience. . . the workings of nature, operating according to ungovernable laws, easily appeared to him, in an aggregate, as the working of God Himself. . . "55

But in the "hominized" world, which began in more recent times, there has been a movement in the history of the mind "away from the world towards man, away from nature towards history, away from substance to the subject and its free subjectivity, in short, away from mere 'cosmocentric' towards an 'anthropocentric' way of thinking. . . "56 As a result, there has been a change in man's relation to and experience of the world. "The experience of man as a speculative world-subject moves out of its inner life to involve itself actively with the world. . . Nature, formerly the one who embraced, has become the one who is embraced. . . its laws are in our hands."57

Is this on-going transition a rejection of religious faith? Not really. In fact from the perspective of this theology, the gradual transition to the creative freedom of man and the secularization of the world was initiated and encouraged by the Christian Gospel. In the classical pagan world god was the imminent principle and regulator of the world, and so the world itself was thought to be "numinous", able to directly reveal and manifest god. The gods were never fully transcendent and divine, so the world could never be fully secular.

But in the Christian Gospel it is said of the creator before whom man stands that "God dwells in unapproachable light" (1 Tim. 6:16). He is in other words infinitely above and distant from his creation. And therefore, "Man's attachment in faith to this God of absolute transcendence . . . actually liberates the world. By constantly transcending the world towards God, faith does not abandon the world but in this transcendence makes it appear constantly in its non-divinity, in its pure worldliness. It loses for it its inner-worldly numinosities and absolutizations and the taboos that arise from them. Faith itself, therefore, produces a fundamental secularity of the world."58

This theology points to still more Gospel seeds of the "hominization" of the world. Another is the centrality in the Gospel of man's historical *freedom*. To a striking degree in the Gospel, the world is not superior to man, or an already finished product, but it is the as yet unformed, rough-hewn material which still and always requires shaping by man's free creativity.

Still another factor is the incarnation of God. The fact that God in becoming human, related to the world and history in his humanity and not in his divinity means that "the world loses its numinously shimmering divinity and is given into the hands and responsibility of man and hence liberated to find its own worldliness".⁵⁹

This "theology of the world" is not another form of unrestrained optimism or utopianism. It is aware of dangers and excesses, and does not uncritically equate all movement towards *hominization* of the world with its immediate and automatic *humanization*. There are and will be deceptions, exaggerations and lags. Man the manipulator of nature can easily become man the manipulated. "Not only is he, as subject, in charge of the hominization process, but he is more and more in danger of himself being degraded to the object of all this planning and experimenting, subjection and regimentation."⁶⁰

What this theology is proposing is not that humanization is inevitable, but that it is possible if the challenge to become increasingly responsible for nature and history is accepted and taken seriously. And that challenge is urgent, inescapable, has its roots in the Gospel itself, and should not be deflected by any rhetoric of fear and uncertainty.

Another theologian (Karl Rahner) expressed these points this way:

Naturally the Church, along with individual Christians must speak out with great determination against all abuses of man's self-creative power. . . . But this danger does not warrant any pre-condemnation of the coming age of self-creation. Nothing is gained by retreating behind negative epithets or rhetoric about shameless barbarism and the destruction of 'nature', and all this accompanied by dirges about the death of life in a technological culture. Nothing is accomplished by weeping over 'pagan' insensibility to sickness, pain, death and poverty, nor by painting the future as an undifferentiated mass society where real history comes to an end among a static and faceless mass of zombies. Such an uncontrolled reaction comes from cowardice masking behind biblical ideals.⁶¹

2. "Playing God", "Playing Man" or "Playing Patient"?

With the above by way of a foundation and background, I have already in large part attempted to respond to or qualify somewhat the "playing God" argument of the "vitalist" option. In

the first place, from the perspective of the theologies just discussed, not even God "plays God" in the world in the sense that expression usually has. He neither "cures" patients nor "causes" them to die. Even if miraculous cures do take place, they are apparently rare and exceptional. Even the faith healer Oral Roberts is at the same time a strong supporter of *medical* intervention and cure.

Responsibility for decision-making and action in the world is left to humans — when they accept that responsibility they are neither playing God nor playing human but *being* human. Since both theology and human experience suggest that God does not in fact directly intervene in the biological processes of life and death or make life and death decisions, humans would be abdicating responsibility to passively leave the care, protection and control of life to God.

To be fully logical and consistent, to not "play God" in the usual sense of the expression would be to invalidate medicine itself. One physician put it this way, "When it comes to many of the social problems of medicine. . . doctors retreat behind the cliché that they won't play God. This type of intellectual cowardice, this mental retreat, is irrational. It lacks logic completely, because through the nature of his work, a doctor is constantly intruding himself into the work of the Deity. Does he wait for God to show his decision by making some outward manifestation before he undertakes a Caesarean section, orders a transfusion or performs a risk-fraught open-heart operation?"⁶²

While I don't agree that those medical procedures are "intruding into the work of the Deity", the thrust of his point is well taken. There are, however, two qualifications one should make here, two occasions or contexts in which a reluctance to "play God" (though not the best expression available, and not to be taken literally) is at least pointing to something important.

The first has to do with the conviction of both moralists and physicians that there are still some limits, there is still some line beyond which intervening with and controlling life should not be allowed to go. Strictly speaking the "don't play God" argument may not be a justified or helpful moral argument against crossing that line (for reasons referred to above), but it does at least suggest that there may be *other* moral arguments to be made against performing one or more therapeutic or experimental procedures in all or some circumstances.

In other words, "playing God" can connote two possible things. The first, the meaning we rejected, is that one is acting like God, taking over his role as intervener in and controller of life *whenever* one intervenes with or fails to support life for any reason whatsoever. The second connotation of the expression, and a more acceptable one, is that for one reason or another the act or omission in question would exceed one's rights, or go beyond the limits or the line finite and ignorant man should go (for instance by the direct taking of life without justifying reason). This for instance is the meaning James Gustafson conveys when he writes, "Man is made in the image of God, and to alter the fundamental image of man is to 'play God', which is not only religious idolatry, but also a movement beyond the healthy recognition of human finitude that keeps various forms of evil in check."⁶³

A second context in which the expression "playing God" points to an important issue is that of the physician-patient relationship. When a patient (or someone else on behalf of a patient) accuses a doctor of "playing God", what is often meant is not really that the doctor is usurping *God's* rights, but the *patient's* rights.

The physician in these instances is in reality accused not of playing *God*, but playing *patient*. In this sense the expression points to the issue of paternalism, the regrettable assumption on the part of the doctor that he or she is entitled to make decisions for and/or withhold information from the patient, because, after all, "doctors know best what is for the benefit of the patient". Paternalism, by general admission of doctors as well as patients, is a too prevalent attitude with far reaching implications for all aspects of health care. It is not of course limited to physicians, but neither does respectable theology maintain that God is paternalistic. Acting paternalistically therefore does not deserve the label "playing God". It should be described as simply what it is — acting paternalistically.

3. Sanctity of Life Principle as a Test of Moral Rules

I have already attempted to refute the claims of the first two options, namely that the sanctity of life principle is equivalent to vitalism, and that it is false and meaningless. It will now be my task to more positively demonstrate what the purpose of the principle is, and that it can and ought to be meaningful and fundamental in biomedical decision-making.

One is inclined to agree with Clouser that the heart (though not the whole) of the sanctity of life principle is "Do not take life without justification." I also agree with Clouser and others (against the "vitalists") that the principle alone still leaves the crucial issue undetermined, namely, when is taking life justified. I would however add that it leaves a great number of other issues undetermined as well, especially all those which can be grouped under the umbrella of the survival and integrity of the human body, mind and species. But I do *not* agree with Clouser and others that because it leaves the crucial issues undetermined and is an abstract principle it is therefore more or less meaningless and deserves to be displaced.

(a) *The role and qualities of abstract principles:
indeterminate, abstract and "higher" than rules*

In establishing that the sanctity of life principle is in fact meaningful though abstract and indeterminate, I am indebted to the views of Henry David Aiken on the role of abstract principles.⁶⁴ Aiken is concerned to demonstrate that there is no single form or theory to which all ethical reasoning can be reduced. Moral discourse takes place in many forms, at various levels, and there are irreducible differences between them in meaning and function. He correctly observes that most contemporary moral philosophers are too prepared to reduce the complexity of human problems and ethical judgments to a single ethical theory or type of theory. That erroneous assumption has given rise to endless and insoluble debates between proponents of competing theories as to what is and is not "essentially" ethical in judgments and language.

He counters such misconceived controversies and the monistic assumption behind them by noting that there are at least four distinctive levels of moral discourse each of which employs terms such as "good", "right" and "ought", and the context of moral argument tends to be a shifting one, going on at more than one level. They are, the *expressive* level, the level of *moral rules*, the level of *ethical principles* and the *post ethical* level.

The *expressive* level refers to our typically unreflective and spontaneous response to any situation. After seeing or hearing something, we like it or dislike it, though we don't always know why. At this level such expressions are spontaneous and personal and they don't involve questions of "truth" or "validity", nor do they call for reasons justifying that what is responded to is really "good" or "bad".

It is at the level of *moral rules* that the ethical questions are asked and answered, that the "ought" is raised, that actions are now examined and evaluated as questions of moral conduct. Two kinds of evaluation are involved at this level. One involves *facts* — what is, and the other involves *rules* — what ought to be. Both are important and not to be neglected.

The factual premises — means, consequences and other empirical data — comprise the context of the rules. But without the application of moral rules we could not have ethical reasoning — "Moral rules still govern the course of our factual reasoning in ethics. . . in the last analysis, they alone determine what factual reasons are to be accepted as relevant. Not just any facts or consequences have bearing upon a moral problem."⁶⁵

Two examples are the questions of when human life begins and when human life ends. Biological/scientific data on the gestational process and on the dying process is interesting knowledge, but as regards the beginning and end of human life it only becomes relevant and essential knowledge if we have prior moral policy definitions of human life and human death. The data alone does not compel any particular moral policy.

But a number of possible causes can raise questions as to whether some action laid down by accepted moral rules is, after all, the right action. The continued validity of the rules can then become open to question and calls for fundamental reconsideration. "Such questions have many causes. It may be that the moral rules conflict; or that a consistent adherence to them would result in general inconvenience or suffering. It may be that they run too persistently against the grain of human need or inclination. It may be that changing social conditions render them inapplicable or inadequate for the adjudication of communal disagreements."⁶⁶

One of the causes which can raise questions about the continued validity of a moral rule is then a change in the "data", a cause very relevant to our biomedical issues. If the empirical data to which a rule has long applied is now changed, is the same rule still able to cope, or is a new one called for? Should the rule be replaced; modified or made more specific? For example, the relatively new ability of medical life support technology to sustain human biological life almost indefinitely, raises the need to at least re-examine the moral rule, "do not kill".

Data or facts pertain both to *present* knowledge or capabilities and to *predictive* extrapolations or projections from what is known and can be done now. Both time-frames require consideration. No existing or potential moral rule or policy in biomedical issues can be properly evaluated without considering both what can be done *now*, what knowledge and powers are likely in the near and distant *future*, and how they are *likely* to be used given various human propensities and historical precedents. "Can we have confidence that men will use their new knowledge and powers wisely, and for the end of human welfare? Or are human propensities for evil so great that we must protect the human race against its own capabilities?"⁶⁷

The question of the validity of moral rules brings us to the purpose and function of the third level of moral discourse, the level of "*ethical principles*", and the sanctity of life principle in particular. There are three important aspects of ethical principles to be considered, each of which helps to clarify their function. The first is that they are *impersonal* — personal bias or preference is not the consideration at this level. "It is their function to establish a mood in which the particular moral code as a whole is considered impartially or, as we say, 'objectively', without regard to our own inclinations or benefits."⁶⁸

A second characteristic is the way the impersonal authority of ethical principles distinguishes them from ordinary practical judgments and demands. With the former the issue is not whether a revision of the moral rules would "benefit" everyone, but whether it would be right to do so, whether it ought to be done.

A third and related characteristic of ethical principles is their *autonomy*. They neither reward with greater happiness, nor threaten with sanctions. Those are the incentives or motives at the level of moral rules. But at the level of ethical principles, "ought" and "right" replace rewards and sanctions.

Nor are ethical principles "justified" in the same way as moral rules. "One may give 'reasons' in support of this or that demand for a change in the moral code. But in the end one can only justify such reasons from an ethical point of view by appealing to ideals or standards which themselves establish what we mean by an ethical reason. To require their justification is simply to go beyond ethics altogether."⁶⁹

One cannot pretend to know how many such principles there are. Nor should appeals for moral reform be justified by appeals to

only one such principle. And, as Hegel noted, it is precisely where there is an unavoidable conflict and collision between two or more "right" principles that we locate true tragedy. It is ethically insoluble because both are "right" and self-justifying. And "the very possibility of tragedies of this sort is itself an index of such a plurality."⁷⁰

To criticize ethical principles for being too "vague" or "empty" to be practically useful is to misunderstand their purpose. They cannot be expected to carry the "moral load" by themselves, to answer questions about what ought to be done in this or that particular situation, as they are often claimed to do or rejected for not doing. Vitalism for instance erroneously makes this claim for the sanctity of life principle, whereas those who reject it often do so because it appears deficient in that respect. One view claims too much for the principle, the other too little.

Both fail to recognize that ethical principles (or "secondary rules" as Mill called them), such as justice, benevolence, sanctity of life, are able to perform their proper function precisely *because* they are relatively indeterminate, and that they are *procedural* more than substantive. "The former [rules of conduct, relatively determinate] are directed to the solution of particular problems of conduct or concerned with the realization of particular goals. The latter [principles, relatively indeterminate], on the contrary, are directed rather to the organization, regulation and correction of lower order attitudes. Second level principles, therefore, are procedural rather than substantive in aim. Their role is not to tell us what to do in particular cases, but to provide us with standards of relevance or 'reasonableness' when appraisal of lower order rules is required. . . ."⁷¹

Only something "higher" than a rule can test or judge rules and be a principle for judging all rules. And if these principles were not abstract and indeterminate they would be simply rules of conduct themselves and we would have an endless list and evolution of rules, but no principle with which to test them. It is what Kant was at least trying to do with his formulation of the categorical imperative. "It is not a rule of conduct but a formula for testing rules of conduct. It had to be 'empty', it had to be formal, if it was to do the job assigned to it. To enrich its content would be ipso facto to transform its role and hence to deprive it of its power as a general principle of ethical criticism. . . . What he saw with unrivaled clarity is that moral criticism which is something more than an ad hoc expression of individual attitudes is impossible save on the assumption that there are ethical principles which are general in normative appeal."⁷²

(b) *Sanctity of life principle as test of rules*

We should now apply these general remarks more directly to the sanctity of life principle. First of all, it too is one of those principles which are "*general* in normative appeal." That is what Shils, St. John-Stewas and others argue when they claim that without presupposing the sanctity of life principle one cannot establish either human rights or the value of human life.

Secondly, the function of the sanctity of life principle is that of *testing* particular moral rules. "If one asks, for example, 'Is it a good rule that abortions ought not to be performed?' — to take a rule which until recently has been part of the western moral rule system — one needs a principle which operates at a higher level than the particular rule in order to judge the validity of the rule. 'The sanctity of life' provides such a principle. Does that particular rule about abortion serve or enhance or exemplify 'the sanctity of life'? That is the kind of question we want to ask about the rule."⁷³ That is the kind of question we want to ask about *all* moral rules (and laws) which affect human life. Do they encourage respect for life? Do they respect what human life really is and really needs?

Thirdly, the sanctity of life principle is *vague and indeterminate, but not meaningless*. We do have only a rough, general, "more or less" idea of what it means. We use in various combinations words such as "worth", "value" and "dignity" when we refer to the principle. It suggests and includes a number of related affirmations and concerns, and there will continue to be debate about some of them.

So it is indeterminate, but as maintained earlier, it must be to do its job. But it is not meaningless, any more than are the principles of justice or benevolence though they too are indeterminate and in many respects are and will continue to be subjects of debate and contention. As noted earlier in the paper the sanctity of life principle does at least "mean" that life is precious, should be respected and protected, treated with consideration, and is a principle basic to our society.

Lastly, if it is the function of indeterminate ethical principles to judge and test determinate rules of conduct, then clearly the principles cannot achieve that goal unless there are in fact such rules. Put another way, the sanctity of life principle would remain for all practical purposes meaningless and useless if it were not given concrete content by the rules which express it and support it. Which

leads me to a brief consideration of the moral rule systems and rules which express and support the principle.

4. Moral Rule Systems and Moral Rules as the Expression of the Sanctity of Life Principle

Obviously a great number of questions could be and should be raised and dealt with in any full treatment of moral rules. It would take us too far afield to do so here in any great detail, but by way of background we should at least note in passing what some of those questions are. One of the most important is of course a determination of the logically necessary and sufficient conditions for a rule to be a *moral* rule as opposed to other kinds of rules.

What is the criterion? Are moral rules those given to us by God? Or is the test a social and cultural one? Is it any rule which anyone insists should be universally obeyed? Or ought the criterion to be that of the utilitarians — the promotion of the greatest happiness of the greatest number? Is a moral rule any rule to which rational men would advocate obedience? On the other hand, are the evil consequences of everyone breaking a particular rule the distinguishing marks of moral rules? And what are the rules generally identified as “the moral rules”? Those most commonly proposed are, “don’t kill”, “don’t lie”, “don’t steal”, “don’t commit adultery”, “keep your promise”, “don’t cheat”, and “don’t cause pain”.

These (and other) criteria of moral rules, and these seven (and other) moral rules have all had and still have their defenders. The arguments for some are more compelling than the arguments for others. But it will not be my task to contribute directly to that important and on-going debate.⁷⁴

By the term “moral rules” for our purposes we intend rules which are wider, more specific and less strict in sense than the seven listed above. In considering the rule systems and rules which could be said to best express, determine and give content to the sanctity of life principle, there are any number of ways and proposals as to how they should be articulated and grouped. One writer proposes that a comprehensive listing would identify rules dealing with:

- the survival and integrity of the human species
- the integrity of family lineages

- the integrity of bodily life
- the integrity of personal, mental and emotional individuality, and
- the integrity of personal bodily individuality.⁷⁵

In my view the list does account adequately for all the rules and issues which could come under the umbrella of "sanctity of life".

Thus the 'sanctity of life' implies a spectrum of values ranging from the preservation of the species to the inviolability of human bodies, from man in the aggregate (present and future) to man as an individual (present and future). The discrete rule systems each serve an aspect of human life: species-life; familial, lineage-life; body-life; person-life; and body, individuality-life. Each aspect of human life, therefore, has an appropriate rule system designed to protect and foster that aspect.⁷⁶

What remains is to identify with more precision some of the specific rules and issues which could fit within those groupings or rule systems. Since this paper's primary area of focus by way of application is that of life preservation of the seriously and terminally ill, and since another interest is the question of genetics, I will not attempt to discuss all five of the above rule systems here. I will deal only with the first three, as they cover rules and related issues expressing the sanctity of life principle in our areas of concern.

(a) *The survival and integrity of the human species*

Moral rules under this heading are particularly (though not exclusively) relevant to issues such as, ecology, nuclear warfare, over-population, genetic engineering and the uses of technology. The primary rule is that *the human species ought to encourage and protect its own survival*. And from this flow subsidiary and more specific rules assigning moral responsibilities to nations and individuals for conduct in all the relevant areas — ecology, genetic engineering, etc. Rules which threaten or no longer adequately encourage or protect the survival of the species ought to be modified or rejected.

A brief look at the issue of genetic screening and genetic engineering might clarify the function of both the rules and the principle. There are first of all questions of *fact*, of empirical data to consider. What do we now know, what can we now do, about genetic characteristics? How reliable is our knowledge and how safe are our techniques? What are the dangers to health and possible benefits to health of DNA research? What are the likely genetic results in terms of future generations if we *do* genetically screen and

genetically engineer, and if we don't? What are the predictable consequences of one means as opposed to another means?

But in judging the validity of old or new rules of conduct there is more involved than empirical data. The more fundamental question is this — what kind of genetic composition, what kind of human being do we want, and do we have a right to want? The scientific data must be as reliable as possible, but the kind of human being we want will determine what data is judged relevant and significant, what distinctive qualities of human beings “ought” to be genetically encouraged, and which characteristics will be judged genetic defects to be cured or modified.

The sanctity of life principle does not answer in detail all these questions and issues. Many of them are and will remain hotly debated. But translating the principle into specific moral rules to promote the survival of the human species does give content to the principle and allow us to reject or modify rules which threaten that survival.

(b) *The integrity of family lineages*

Moral rules in this category would deal particularly with these issues: artificial insemination, sterilization, genetic engineering, and contraception. And again they both express and are tested by the sanctity of life principle. The primary moral rule here might be expressed this way: *Families and individuals should not be hindered from propagating children and perpetuating their family lineage.* Subsidiary and more specific rules are those which prohibit other individuals or the state from obstructing one's free choice to procreate or not, to “parent” or not, and to choose one's own manner of procreation or contraception.

Once again both facts and values must be considered, and rules judged and formulated by considering both. On the level of facts, the question is what are the technical/scientific possibilities and the consequences for individuals and society now, and in the likely future, of certain procedures and methods? Is cloning humans possible? What would be its likely long range effect on the “gene pool”? What methods of sterilization are available and what are their physical and emotional short and long range effects? What percentage and kind of genetic defects are in fact inherited? Would sterilization of sexual offenders really lessen their danger to society? What costs to society in terms of money and services are involved?

But on the level of value choices can a real or supposed benefit to society over-ride the procreative rights of an individual or of a particular group — *i.e.* sexual offenders, or the mentally retarded? To what extent if any ought financial cost to society to condition restrictions of rights to procreate and parent? What is “normalcy”, what is “deviancy”, and who (if anyone) should decide?

(c) *The integrity of bodily life*

Under this heading may be grouped moral rules which relate to subjects like euthanasia, abortion, and termination of treatment. The primary rule would be that *neither individuals nor the state may unjustly take human life*. And the subsidiary, more specific rules are those which articulate the particular obligations, prohibitions and protections of the various groups or individuals who might be involved as decision-makers or as those affected by decisions — patients, physicians, nurses, families, hospital administrations, etc.

Here too there are questions concerning evolving technical data, and those involving value choices. The issues of abortion and the prolongation of biological (brain dead) human life for instance, call for evaluations and predictions of data concerning the process of gestation, the present and likely functional levels of patients with extensive brain damage, the accuracy and possibility of medical prognoses and the likely short and long range therapeutic and restorative effects of “artificial” life support systems, etc. But there are essential and value-laden definitional questions involved as well. The obvious ones are, what is human life and human death and what signs will be accepted as normative of each, both at the beginning and end of life? Is there a right to die, and a right to refuse treatment? Is there a distinction to be made between human biological life and human personal life? If so, what implications follow for rights and needs in health care?

The sanctity of life principle by itself cannot answer all these questions, but it does at least help to raise the right ones, and to establish and test some parameters, some lines for the rules. And the particular moral rules in their turn give content to the principle — not only human life “in general” is to be protected and respected, but individual bodily life.

D. Conclusions: the Relevance for "Quality of Life"

(1) One can hardly have failed to note that in each of these three rule systems, there is one predominant theme running through all the value questions which weigh the data and probe the adequacy of the rules — what *kind* of human, what human *condition*, what human *qualities* do we want, do we value, ought we to protect? What genetic qualities, what kind of families, what level of "deviance", what level of function should we consider normative and desirable? What criteria for death, what kind of dying, what definition of person should we opt for?

(2) The data is essential, so are the rules as concrete expressions of the sanctity of life principle. But data cannot be evaluated, and the rules cannot be formulated or reformulated unless we recognize the legitimacy and urgency of *quality* concerns in the context of human life and death, and establish our quality choices first of all.

(3) The data and the technology present us with a growing number of options regarding the kind, condition and quality of life now possible and to come. The options require choices, and the choices are as much and as inescapably about quality as about only existence or quantity.

(4) Quality choices related to technology may have been less pressing and more avoidable in a simpler age, but now in more and more cases, *not to choose is to choose*. To avoid principled choices between competing technologies and social policies, choices made partly at least on the basis of the different qualities of living and dying they promote, is often in effect to choose the least desirable, the least moral — if not for this generation, then the next. If the "quality" choices are made by default by the technocrats and bureaucrats, because the rest of us assumed it was enough to occasionally burn incense before the "altar of the sanctity of life", then we have misunderstood both that principle and our responsibility.⁷⁷

That said by way of conclusion to the first part of the paper, let us now consider in some detail the concept of "quality of life".

*Vex not his ghost, o let him pass! He hates him that would
upon the rack of this tough world stretch him out the longer.*

— Lear

*Who shall live and who shall die, who shall fulfill his days
and who shall die before his time. . .*

—Yom Kippur
(Day of Atonement
prayer book)

*. . . he remembered how the old folk used to die back home
. . . They didn't puff themselves up or fight against it and
brag that they weren't going to die — they took death calmly.
They didn't stall squaring things away, they prepared
themselves quietly and in good time, deciding who should
have the mare, who the foal. . . And they departed easily, as
if they were just moving into a new house.*

— A. Solzhenitsyn

*Let sanguine healthy-mindedness do its best with its strange
power of living in the moment and ignoring and forgetting.
Still the evil background is really there to be thought of, and
the skull will grin in at the banquet.*

— William James

PART II

THE QUALITY OF LIFE

Chapter 3

The Quality of Life and Death

As noted in the first section, the sanctity of life principle is itself somewhat elusive and indeterminate. It is not however totally without substance and meaning, both in terms of what it means and does not mean. It *does* point to an objective, absolute value of human life and worth, it insists that human life is always worthy of respect and protection, and that it should always be supported without adequate justification to the contrary. Inasmuch as these assertions have always been and still are under attack in open or subtle ways in medical, legal and other debates, the sanctity of life principle continues to require articulate and strenuous defence.

But it does *not* mean vitalism, it does not preclude the need for human decision-making and judgment, for instance in decisions to medically treat or not to treat, to preserve or not to preserve life, in

certain circumstances. But if this is so, what exact role has the *kind* of life, the *quality* of life in question to play in that decision-making? The sanctity of life principle is not by itself concrete and determinate enough to answer all the questions, to solve all the problems. Its primary and indispensable role is to establish parameters and priorities for debates and decision-making involving human life, and to judge and test relevant moral rules. But it needs the moral rules to make it concrete and useful in particular cases. The principle acknowledges that there can be "justifying reasons" for ceasing to preserve human life and (some would say) even for taking it. But it does not indicate clearly what those justifying reasons are. And it does not define for us what human life really is; what its essential qualities or inherent features really are.

Not to face those questions directly would be to avoid doing our "moral homework". To use the sanctity of life principle as a tool to determine all moral decisions in advance without any consideration of further questions and individual circumstances, is therefore to distort the real role of that principle and to use it as a decision-avoiding, not a decision-making tool.

But if this is so, how useful and morally legitimate is the "quality of life" concept in helping to shape moral rules, in determining "justifying reasons" for both preserving and ceasing to preserve human life, and in establishing the inherent features of human life?

A. An Elusive Concept—Subjective or Objective? Absolute or Relative? Equal or Unequal?

The answer of course depends upon what is meant, or what meaning *we give* to "quality of life". What makes the question one of practical relevance and not just academic interest is that quality of life concerns are already and long have been influencing medical decisions. But what makes the question an urgent and somewhat worrisome one for society, medicine and law is that quality of life can and does mean many very different things, has no single, generally accepted meaning, and some of its connotations and the uses to which the concept is put are definitely opposed to and in conflict with the sanctity of life principle as outlined earlier.

It is probably its very elusiveness which makes the concept so attractive to media and public. It is so vague and glibly used in such quite different contexts (environmental and medical for instance) and in support of such quite different positions (for instance to improve the quality of air, or to cease medical treatment) that the concept seems to commit one to nothing specific, and is seldom given tangible content.

But its very elusiveness encourages as well the polarized, extreme and hostile views about its moral legitimacy and usefulness. There are those who think it answers all questions, and those who think it answers none. There are those who would welcome the replacement of the "traditional" ethic of the absolute value of human life by an ethic of its relative value. There are others who see any recognition of quality of life factors as a danger to be resisted at all costs.

But it is also possible, and in my view legitimate and preferable, to see no need to choose between an old ethic and a new one. Instead, to recognize an urgent need to on the one hand articulate and refine the "old" ethic, and on the other hand to propose a carefully delineated and restricted meaning and purpose for quality of life. The purpose of such an exercise would be to encourage both medical decision-making and (perhaps) law-making to more formally recognize an interest in considering and protecting *both* the intrinsic value of each human life, *and* the quality of those lives, even when this involves a decision to cease or not initiate treatment or life support.

But to make this case successfully depends first of all of course on the meaning we intend for quality of life. The clarification, justification and application of the meaning I intend for this expression will, from various angles, be the task of the remainder of this paper.

I will begin by very explicitly parting company with the most frequently proposed meaning or connotation of quality of life in the medical/health context — namely that it must inevitably and fundamentally involve more or less wholly *subjective judgments about the relative individual or social worth, value, usefulness or equality of the lives of persons*. Both proponents as well as opponents of the quality of life concept generally assume or claim that such notions are at the centre of the concept. There is little doubt that it is exactly that unqualified assumption on both sides of the argument which gives quality of life such a "bad press" and

raises fears of "playing God" with human lives. If the concept is to serve the useful function it can and must, it needs rescuing as much from its proponents who claim too much for it as from its opponents who claim too little. Inasmuch as the sanctity of life principle insists that the respect and protection due to human life ought not to be based on judgments of relative worth, value or usefulness, such versions are rightly seen as opposed to and judged wanting by, the sanctity of life principle.

Proponents of such views of the quality of life concept are often well aware of this opposition and applaud it. For instance this editorial entitled, "A New Ethic for Medicine and Society" in *California Medicine*, the official journal of the California Medical Association:

The traditional Western ethic has always placed great emphasis on the intrinsic worth and equal value of every human life regardless of its stage or condition . . . This traditional ethic is still clearly dominant, but there is much to suggest that *it is being eroded* at its core and may eventually be abandoned. . . there is a *quite new emphasis* on something which is beginning to be called the quality of life. . . It will become *necessary and acceptable* to place relative rather than absolute values on such things as human lives, the use of scarce resources and the various elements which are to make up the quality of life or of living which is to be sought. . . ⁷⁸ [emphasis added]

The writer may be correct in observing such a shift in practice and/or values. But one need not agree with him on several other counts — that the shift is a good thing, or that his characterization of quality of life is the only one possible or that the "traditional ethic" is unconcerned about quality of human life considerations.

Opponents of quality of life considerations in medical life and death decision-making, just as its proponents, generally assume the same reductionist and unqualified meaning of quality of life when they characterize it as opposed to or incompatible with sanctity of life. For instance, this view of a moral theologian:

The quality of life ethic puts the emphasis on the type of life being lived, not upon the fact of life . . . What the life means to someone is what is important. Keeping this in mind, it is not inappropriate to say that some lives are of *greater value than others*, that the condition or meaning of life does have much to do with the justification for terminating that life. The sanctity of life ethic defends two propositions: 1. That human life is sacred by the very fact of its existence; its value does not depend upon a certain condition or perfection of that life. 2. That, therefore, all human lives are of *equal value*; all have the same right to life. The quality of life ethic finds neither of these two propositions acceptable.⁷⁹

Once again, as stated and without further qualification there may well be opposition between *his* characterizations of sanctity of life and quality of life; at least a difference in stress. But we are not obliged to accept either of his characterizations as the only or most accurate ones possible. In the light of this paper's earlier efforts to distil the meaning of the sanctity of life principle, one is inclined to classify the above description of that principle as verging on vitalism, — leaving as it appears to, no room for concerns of the "kind", "quality" or "condition" of a life. And below I will attempt to demonstrate that a more qualified and restricted meaning of quality of life than that presented above does not really find those two sanctity of life propositions "unacceptable" — only "insufficient".

B. "Quality of Life" in the Environmental and Medical Contexts—A Comparison

Before coming back to these points and an arguable "definition" of quality of life in greater detail, we should briefly consider the meaning of the concept in another kind of context — that of environmental, ecological or social concerns. Much of the difficulty and ambiguity of the expression in the medical context stems from the fact that we too readily and uncritically use the same expression in two very different circumstances and for two very different purposes. One result is that the concept appears to be positive in one context — the environmental/social, but negative and reductionist in the other — the medical. But another result is that in exaggerating the differences in context and purpose in the use of quality of life, we may overlook some important and useful common denominators and insights.

A brief summary of the state of the quality of life question in contexts other than the medical is therefore in order. First of all, quality of life in those contexts focuses on *improving* the quality of life for members of a society or region — better air, food, privacy, water, education, leisure, working conditions, health and so on.

In those contexts, efforts to measure and improve the quality of life have been generally welcomed as a long overdue corrective to almost exclusive concentration on factors such as production,

economic growth and gross national product. "The concept 'Quality of Life' has emerged in the last few years as an undefinable measure of society's determination and desire to improve or at least not permit a further degradation of its condition. Despite its current undefinability, it represents a yearning of people for something which they feel they have lost or are losing, or have been denied, and what to some extent they wish to regain or acquire."⁸⁰

But in the environmental/ecological/social contexts the 'life' being evaluated is not "John Smith's" life, but life in a particular society or region. As Kurt Baier points out, quality is a comparative property. It involves comparison with other things. But the things compared are not particular lives, but the "relevant environmental conditions of life" in a certain region. "Those who choose regions on the basis of the quality of life there, will... appraise the conditions of this, *i.e.*, the aspects of the physical and social environment which affect how good or bad any person's life is, in so far as that depends on the environment in which he lives. And the aim with reference to which the various types of environments will be appraised is their capacity to make the lives of those living in them as good as possible, or at least enable them to do so."⁸¹

Appraising, measuring and improving the relevant conditions, depends of course on the determination of and agreement upon social indicators, standards and operational definitions. A difficult if not impossible task, and no effort to establish indicators or an index of quality of life has as yet gained universal support. A number of attempts have been made with more or less success.⁸²

Proposed indicators attempt to determine not only environmental factors, but also economic factors and sociopolitical factors (such as health, social relationships, equality, education, community, etc.). Many of the approaches are subjectivist, in that they stress subjective data such as "perceived" happiness, satisfaction or fulfillment in the social indicators stressed, and they attempt to determine the quality of life in that region or society by questioning people about their satisfaction or happiness.⁸³

But others convincingly argue for an *objective* approach maintaining, "... that it is possible to combine within a single conceptual or methodological framework, the notion of a subjective 'indicator' of the Quality of Life with what is 'constitutive' of the Quality of Life, the latter being wholly non-subjective."⁸⁴

This view defines quality of life and its indicators not just in terms of general average happiness or the sum total of happiness of

people in a region or society, or just in terms of tastes or preferences. These are all subjective factors. Central to this view is that quality of life is not just the happiness of a region, but the necessary conditions for happiness. Clearly both objective and subjective factors are relevant to quality of life — for instance salary and satisfaction with salary in the context of working conditions.

But quality of life is not really a combination of objective factors and subjective factors. "We might as well say that the quality of a fabric does not lie in the fabric, but consists, instead, in some esoteric combination of properties of the fabric together with pleasurable feelings on the part of the wearer. No, the quality of a fabric lies in the fabric, and the quality of working life lies in working conditions. The role played by job satisfaction indicators is to indicate 'which' working conditions are important in determining the quality of working life."⁸⁵

The same point can be made from another angle. How are "general happiness requirements" satisfied? Is it by the satisfaction of human needs, or human desires? "... we might say that *wanting* and *desiring* are 'psychological states', whereas the state of *needing* something is not a psychological state. Combining this result with the one obtained earlier about the non-subjective character of the Quality of Life, we are able to infer something about the general happiness requirements. The Quality of Life, as we have defined it, consists in the fulfillment of the general happiness *requirements*. Since the presence or absence of unsatisfied wants is a mental or 'subjective' phenomenon, fulfillment of the general happiness requirements cannot lie in the satisfaction of human *wants*. If anything, it must lie in the satisfaction of human *needs*".⁸⁶ [emphasis added]

And what do humans need in order to be happy? One of the best known attempts to propose a hierarchy of human needs is that of Abraham Maslow.⁸⁷ He proposes these five categories:

1. Physiological needs;
2. Safety or security needs;
3. Belongingness needs;
4. Esteem needs;
5. Self-actualization needs.

No argument has yet established that Maslow's list of needs, or some such list, cannot be predicated for all people in all places. That being the case it could provide a good first step to providing objective indicators or criteria for the quality of life.⁸⁸

One last point in this regard, concerning the relevance of "taste" or "personal preference" to quality of life. The fact that different people will have different "optimal lives", different rational goals, is partly due to differences in individual tastes. Yet the determination of what is a person's optimal life is not just a matter of taste and can be given an objective answer.

Whether the contemplative life is the best life is a matter of taste, but we can in principle tell what sorts of people will have what sorts of taste, and so objectively what sorts of lives will be optimal to them. . . there are some things that can be said about all optimal lives, whatever peoples' talents and tastes. We have as yet no pre-test indicators enabling us to say whether Jones or Smith will find Sacher Torte the best cake, but we can confidently predict such things as that they will not like their favourite dessert laced with DDT or mercury, as some of our foods now come to us.⁸⁹

What has all this to do with quality of life in the medical/health context? A number of things. In the first place it is true that quality of life criteria in the environmental/ecological/social contexts are used for the comparing of *environmental/social conditions* in order to *improve* them; whereas in the medical context they often seem to be used to compare *human lives* but not as grounds for improving, rather for *terminating* them. In the former contexts, quality of life involves a protection and expansion of life in all its forms, styles and levels; whereas in the latter context it suggests a limiting, qualifying, reductive and standardizing impulse.

As used by some in the medical/health context, quality of life suggests that some of the sick and "defective", because they are no longer able, or will not be able to contribute to society, therefore no longer qualify to benefit from the environmental and medical resources as do the rest of us. Quality of life thus compared in the two contexts comes off a very poor second in the medical/health context.

But as stated earlier, what is intended here by quality of life is, among other things, a notion purged of any trace of *relativizing human worth* and the lives of persons, or any hint of "social utility" as a necessary qualification for treatment. And just as in the environmental context it can focus on *objective* factors, criteria and needs, so too in the medical context. Examples of objectivity in criteria, are efforts to "define" person and to formulate criteria for "ordinary" and "extraordinary" treatment, both subjects we will consider below. And just as in those environmental/social contexts, quality of life decisions in the medical context can and should be oriented to *improvement and benefit* — in this case, of the patient.

Quality is a comparative property, an evaluative property. And it is true that quality of life used in environmental/social contexts does essentially involve a comparison with other things — a ranking of the conditions which maximize optimal human life or general happiness requirements of a region. Implicit in the comparison is a readiness to discard or improve certain conditions because of where they rank on the scale.

But in the medical/health context, quality of life *need* not involve a comparison of *different human lives* as the basis for decisions to treat some and not others. Ideally, at the heart of quality of life concerns in this context should be only a comparison of the qualities *this patient* now has with the qualities deemed by *this patient* (or, if incompetent or irreversibly comatose, by the patient's agents) to be normative and desirable, and either still or no longer present actually or potentially.

The real comparison in question is in a sense one between what the patient is and was, is and can or cannot be in the future. The quality of life comparison or evaluation in the medical context need not be a comparison *with others* or a relativizing of persons' lives. And the quality of life norm and decision need not be arbitrary or based upon how treatment or non-treatment will relieve or burden others or society. The norm can and must include whatever the value sciences, medicine and public policy agree upon concerning the essential quality or qualities of a human person; and the decision can and must be in the first instance by, and for the benefit of the patient and no one else.

To include quality of life considerations in life saving or life support decision making by no means must imply *harm* rather than improvement or benefit to the patients. If quality of life is limited only to what is intended here, then quite the contrary is the case and must be the case if the concept is to have any justifiably normative value.

In the first place, investigations, prognoses and conclusions arrived at concerning a patient's actual or potential level of function or degree of suffering, need not inevitably and exclusively lead to decisions *to cease* or *not initiate* life supporting treatment. Given that the sanctity of life principle imposes the burden of proof on those who would cease to support life, the consideration of quality of life factors should more often lead to the opposite decision — to initiate or continue that treatment if there is any realistic hope of minimal human function and controllable pain and suffering.

Secondly, even when quality of life factors do contribute to a decision to cease or not initiate life saving or supporting treatment, there remains the continuing obligation to seek to improve the newborn's or the patient's *care and comfort*. Neither physician nor patient are usually faced with only two options — to continue or discontinue life support treatment. The third option and continuing responsibility of health care professionals and families, no matter how damaged the patient's condition, is to seek to improve the level of care and comfort of the dying, including being physically present to them. The sanctity of life surely calls for at least the same respect and consideration for dying life as for healthy life. And if greater needs call for greater care and concern, then the dying deserve more, not less of it, than the healthy.⁹⁰

Thirdly, even decisions to cease or not initiate life saving treatments, based partly on quality of life considerations, can and must offer a reasonable hope of *benefit* to the patient. In other words, death should not always be resisted at any cost in terms of present and future suffering and damage, as if anything is an improvement over death. It is an integral part of my thesis that this is not so, that some conditions of human life are so damaged, and will likely remain so or become worse if treatment is continued or initiated, that death can reasonably be seen as beneficial, as an improvement for that patient.

The final weighing and balancing of reasons and criteria normally belongs to the patient, and within morally acceptable parameters different patients may and will weigh the criteria differently and come to different decisions. For the incompetent, the determination of benefit to patient or newborn must be made by proxies. While it remains enormously difficult to make such decisions in the interests and for the benefit of others, it is my contention that they must sometimes be made, and that reasonable and morally justifiable decisions for the benefit of others, based partially at least on quality of life matters, are possible. There will be occasion to come back to the "who decides" question and the other points in more detail as the argument unfolds.

In the light of the above, quality of life in the medical context need not come out the loser when compared to quality of life in the environmental/social context. As noted, there are of course great differences in the contexts and the functions within them of quality of life criteria. But in both contexts the ultimate aim of these criteria is objective improvement and benefit, even if in the medical context

that will often be limited to reducing rather than eliminating the patient's discomfort and indignity. In claiming this, the medical cases envisioned are primarily those in which the quality of life criteria are used in decisions made *by others* for the incompetent patient. In such cases the use of these criteria for the patient's objective improvement or reduction of discomfort or some other benefit is a realistic aim. Obviously it may be otherwise for patients able to *themselves* accept or refuse treatment. Since, as I shall argue below (see "Treating and Dying"), competent patients have the right to refuse treatment on any grounds at all, whether they seem reasonable or foolish to others, there can be no guarantee at all of objective improvement and benefit in the decisions made and criteria used by competent patients for themselves.

Just before attempting to put flesh on the dry bones, to offer more argument for the claims made, the thesis of this quality of life section of the paper should be summarized.

Quality of life need not mean the "relativizing of lives". Excluded here in this paper from that concept and its criteria are considerations such as social worth, social utility, social status or relative worth. The sanctity of life principle rightly insists on the intrinsic worth and equal value of every life. In excluding these elements from the meaning intended for quality of life, one need not of course deny that they can be ingredients of quality of life in wider contexts than our own. At least some of them are factors which a "general" quality of life theory must consider and weigh in other contexts. I am only excluding these factors from this particular context of medical decision-making in life and death matters, and primarily when such decisions are made by proxies or patients' agents for patients or newborns unable to make these decisions themselves. Whatever the merits and realities of characteristics such as social status in other areas of concern, here I do not believe they should have determinative weight.

New circumstances such as increasingly sophisticated life support systems and treatment have challenged us to recognize in human life a distinction between mere existence and quality with more clarity than previously needed. But that does not mean that in our context the shifting sands of new medical technology, evolving social realities or subjective preferences comprise an adequate source for the meaning and criteria of a quality of life concept, or in themselves validly answer our questions. What is involved here, or should be, is a search for and a weighing of the *inherent features* of human life. That is an objective meaning of "quality" light years

away from mere considerations of relative and changing circumstances, facts and values. It does not make the task easier, or ensure an immediate consensus but at least the task is defensible.

In this sense, meaning and criteria for quality of life in life or death decision making, should focus not on features or conditions which permit patients to act comfortably, well and without burdening others or society, but rather on features and conditions which allow them to act *at all*, even to a minimal extent. The real question and issue raised by considerations of quality of life is not about the value of this patient's *life* — it is about the value of this patient's *treatment*.

The meaning and criteria of quality of life should focus on *benefit to the patient*, and in some circumstances to initiate treatment or prolong or postpone death can reasonably be seen as non-beneficial to the patient. One such circumstance is *excruciating, intractable and prolonged pain and suffering*. Another is the lack of capacity for what can be considered an inherent feature of human life, namely a *minimal capacity to experience, to relate with other human beings*. In such instances to preserve life could in some cases be a dishonouring of the sanctity of life itself, and allowing even death could be a demonstration of respect for the individual and for human life in general.

The above can be clarified and justified from a number of angles. The first point to establish is that there is a distinction to be made between human *biological* life and human *personal* life. On that distinction hang some important conclusions.

C. Life: A Good in Itself? Death: How "Define" It?

In the context of our concerns the question which raises a need to recognize a distinction between human *biological* and human *personal* life is this: is biological or metabolic life (alone) a *good in itself*, a "bonum honestum" to be preserved regardless of any capacity for conscious experience and communication? Or is physical, metabolic life to be seen mainly as a "bonum utile", a *condition* for other capacities such as experiencing and interrelating, and as such a life which has already achieved its potential or never can if those capacities are no longer or never will be possible?

There are many who answer yes to the first question and no to the second. Some of them were cited earlier in the sanctity of life section of the paper when "vitalism" was discussed. Generally speaking they insist that the real value of human life is in its very *existence*, not in its *capacities or qualities*; and that every life is of equal value. But there are many who hold the second view against the first, arguing for instance that, "Since human life is the condition for the realization of human freedom, it should be prolonged with all appropriate and reasonable means insofar as prolongation according to a competent estimate can serve this goal".⁹¹

Clearly what is involved here is the need to clarify the ambiguous word, "life". Of humans it can mean two related but very different things. First of all "life" can mean vital or metabolic processes without any specifically "human" function or capacity. This could be called *human biological life*, or human physical life or human "technical" life (the latter if medically life-supported).

Such life is still human in the first sense — it was born of humans and is a potential source of human organs. But such life is no longer, and in some cases never will be human life in a second sense, that is a human life also capable of experiencing, communicating, or being responsible for its actions. This we could call *human "personal" life*. From the ethical/ontological as well as the medical standpoints, the real and crucial question in decision making is not whether the patients or newborns are human (they are) but whether they are any longer, or can ever be, "persons".

Drawing the line between these two senses of human "life" is not always of course clear or easy. Two related cases in which it is relatively clear and easy (at least in principle if not always in medical diagnoses) are those of brain death in adults or children and cases of anencephalic newborns (those born without a brain). If human personal life is defined as life capable of a minimal function of experience and communication (a point I will explore and defend in greater detail in the section on "person") and the brain is what makes that possible, then whole brain death is really equivalent to the death of the person.

A human with whole brain death does not, or should not raise any ethical difficulties as regards initiation or continuation of treatment. Death may be declared in such cases once the standard and careful medical tests have been made, even though other "vital organs" (heart and lungs) may be kept alive to that point (and even after for transplant purposes) by life support systems.⁹² As for

anencephalic newborns, they too are best classified as instances of human biological, not personal, life and could therefore be deemed "personally" dead at birth. They are generally not in any case paradigmatic cases for cessation of treatment, since such organisms very soon die anyhow, with or without treatment.

Other cases are much more difficult. One in particular is the (apparently) irreversibly comatose patient with massive destruction of the higher brain (cerebral centres), and therefore permanent loss of the ability to experience and relate. Many of these latter are incapable of spontaneous respiration. As we shall see later their cases are difficult enough to resolve. But far more difficult still are those with the same cerebral (higher) brain damage, but able to breathe spontaneously thanks to more or less undamaged lower brain functions. Are they alive or dead according to the above distinction between human *biological* and human *personal* life?

In my view, if the medical tests have in fact determined that there is no potential for spontaneous cerebral brain function, even if spontaneous respiration continues, then the human person is dead. Obviously this view is based on the conviction that man is essentially more than a biological "respiratory" being, and is essentially a rational, experiencing, communicating being. It is based as well on the strong medical evidence that the specific loci in the brain in which these latter functions reside are the cerebral or higher brain centres. From this perspective of course statutes defining death in terms of "whole brain" death (which all of them to date do) do not go as far as they (morally at least) might and perhaps should. In order to legally acknowledge and establish as death this difficult and not infrequent case, statutes would have to require (only) the irreversible cessation of total spontaneous *cerebral* function, instead of the death of the (whole) brain.

On the other hand, from a prudential point of view of course there may well be some good reasons in favour of settling for a whole brain death standard in any proposed statute. There are after all other stances in our society which accept (mere) biological life as personal life, and in an issue as fundamental and contentious as this one, in a pluralistic society like ours, the variety of stances cannot easily be ignored or wished away in the shaping of public policy.

Because of this variety of views it has been suggested that the choice of standards for determining one's death be left to each patient or patient's agent to make, and that legal "definitions" of death be framed with that aim in mind. But in view of the

impracticality of such an approach, the best course for now may well be to stay with the generally more acceptable "whole-brain" death standard in present statutes regarding the determination of death.

Another factor which could be advanced against a "cerebral" death criterion is a very practical and frightening one. It is the general and understandable revulsion at the prospect of burying or cremating a body in which respiration and circulation continue, even though cerebral function has irreversibly ceased. To do so would, at the very least, be an act of grave disrespect towards the body and the memory of the person concerned. It is a serious problem, and one seldom dealt with by proponents of a cerebral death criterion.

On the other hand, that understandable revulsion need not be a definitive argument against considering such a person dead and acting accordingly. We say this because "acting accordingly" need not and should not mean burying a body in which the heart is still beating, but could at least involve ceasing treatment, nourishment, resuscitation attempts, infection-fighting and so forth. In short it would mean stopping anything which would uselessly prolong respiration and heartbeat by extending mere biological life in a body now no longer capable of even experiencing pain or comfort. For more on the treatment and care implications of this problem, see Chapter 5, "Treating and Dying".

In this writer's view the best (whole brain) statutory "definition" of death proposed to date is that of Capron and Kass, first proposed in 1972. It states,

A person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice, he has experienced an *irreversible cessation of spontaneous respiratory and circulatory functions*. In the event that artificial means of support preclude a determination that these functions have ceased, a person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice, he has experienced an *irreversible cessation of spontaneous brain functions*. Death will have occurred at the time when the relevant functions ceased. [Emphasis added].⁹³

This formulation has a number of positive features. Among them are these:

1. It acknowledges the importance and validity of brain death as a criterion of death, even though it could have gone further by acknowledging cerebral death (alone) as personal

death. It could probably be adequately amended to that end by changing the word "brain" to "cerebral", and by not limiting the use of this criterion only to instances of artificial means of support. After all, if spontaneous breathing is still possible then presumably at least that function is not being artificially supported.

2. It avoids any suggestion that there are two concepts or kinds of human death — respiratory/circulatory death and brain death. Instead it proposes two alternate criteria for determining the *single* event and phenomenon of personal death. From a moral perspective it is incorrect to argue or suggest that there are different human deaths, or that because different cells and organs die at different times death is a continuing process or that the moment of death is arbitrary. Terms such as "brain death" or "cerebral death" therefore do not (or should not) suggest only the death of that organ or part of it, but the altered moral status — from personal life to personal death — of the entire individual human being.

3. It recognizes that in most instances of death the usual criteria (respiratory and circulatory functions) remain applicable, and that it is in relatively rare and special circumstances that the direct determination of brain death becomes necessary.⁹⁴

By way of an aside, it should be acknowledged that increasingly death in practice *appears* to be anything but a "single" and "personal" event. This is especially so in the hospital context. As Philippe Ariès writes,

Death in the hospital is no longer the occasion of a ritual ceremony, over which the dying person presides amidst his assembled relatives and friends. Death is a technical phenomenon obtained by a cessation of care . . . Indeed in the majority of cases the dying person has already lost consciousness. Death has been dissected, cut to bits by a series of little steps, which finally makes it impossible to know which step was the real death, the one in which consciousness was lost, or the one in which breathing stopped. All these little silent deaths have replaced and erased the great dramatic act of death, and no one any longer has the strength or patience to wait over a period of weeks for a moment which has lost a part of its meaning.⁹⁵

My major point is that once the distinction between human *personal*, and human *biological* life is made and the line drawn, neither moral theology nor moral philosophy require us to maintain human biological or metabolic life for its own sake as a "good in itself", as if its condition or quality were irrelevant.

In a sense, despite the ambiguities, complexities and debates which persist, that distinction is probably the easiest of all issues with which to establish the principle that human life is not always a "good in itself". But cessation of treatment in the face of and because of personal death is one thing. We have yet to argue in detail (though we began to in the previous section) that sometimes the prolonging of life is not a good or a benefit to the subject even when human personal life does exist, and this because of the degree of handicap and/or level of suffering and/or irreversible imminence of death. It will be the task of most of the rest of this paper to explore and argue this point and its implications around the harder cases as well.

A great deal of experience and even some empirical data⁹⁶ suggest that it is not so much life in itself which we desire, but bearable, enjoyable and worthwhile experiences and satisfactions. We want life for what can be done with it, not for what it is in-itself. "It always seems to be assumed that life, of whatever quality, is the most priceless of possessions. Physicians often assume that patients would always prefer life no matter how handicapped, to death. The opposite is often the case."⁹⁷

But does not this view and the general use of quality of life language imply that there is an *inequality* between lives, and in the degree of protection they therefore merit? "Can one really use a condition of life criterion and still insist that every life is of equal value regardless of condition? . . . does not one statement cancel out the other in the actual ethical climate in which today's debate is taking place?"⁹⁸

Again, the answer to this objection depends upon the meaning we give to the word "life". If "life" means "person" or personal life, then there is no inconsistency or inequality. All *persons* are of equal value no matter what their condition. But not all *lives* in the biological sense are equally of value to the individual person concerned, particularly (though not only) those alive merely in a vegetative or metabolic state.

Because of different (biological, physical) conditions and in respect to decisions about whether and how to treat, all lives are *not* equal if equal means "identical". "What the 'equal value' language is attempting to say is legitimate — we must avoid *unjust* discrimination in the provision of health care and life supports. But not all discrimination (inequality of treatment) is unjust. *Unjust*

discrimination is avoided if decision making centres on the benefit to the patient, even if the benefit is described largely in terms of quality of life criteria."⁹⁹

D. Death with Dignity

Is there any help to be found for our case in the expression and meaning of the oft heard phrase "death with dignity"? Is the reality it indicates a compelling argument for the use of quality of life criteria for the benefit of the patient? Many think it is, and write of the basic indignity done to patients for whom the end comes, "while comatose, betubed, aerated, glucosed, narcosed, sedated, not conscious, not even human anymore."¹⁰⁰

These views usually identify the indignity in both the patient's helplessness, and in the mechanical substitutes which act for and on the patient. "There is an implicit indignity in the conception of the meaning of life revealed by over-vigorous efforts to maintain its outward, visible and entirely trivial signs. It is not breathing, urinating and defecating that makes a human being important even when he can do these things by himself. How much greater is the indignity when all these things must be done for him, and he can do nothing else. Not only have means been converted into ends; the very means themselves have become artificial. It is simply an insult to the very idea of humanity to equate it with these mechanically maintained appearances."¹⁰¹

But if restraining these so-called "heroic" means lessens at least to some degree death with *indignity*, is the more "natural" dying and death which remains therefore a dying and death with *dignity*? Again, many would say, yes. A certain dignity in dying is professed to be inevitable and essential. To accept it is to accept the natural world, life and death the way they are for all contingent beings. Human death is for the good and progress of the group, the larger community, both its biological and societal good.

The community requires continuing rejuvenation, and it is in the enduring human community, not in the transient, contingent individual, that unities and values of the spirit continue. Such for instance was the view of Hegel and is the view of many contemporaries of many disciplines. Not that he and others today claim death of individuals is a dignity, a benefit only for the larger

community of man. In old age for instance, the loss of vitality and creativity, as well as the increase of disease and of monotony underline the limits of finitude and make of death a necessary, natural and welcome culmination to the individual.

In this view death itself is neither unnatural nor the real enemy of medicine. In the natural order of things, physical immortality would be an absurdity and decidedly non-beneficial to both individual humans and the community. The natural enemy of medicine is not death itself, but "... it does make sense to see a painful death or a premature death (less than the usual life span) as 'unnatural' in the sense of violating a reasonable human hope — for a painless death and an average life span."¹⁰²

But there is another side of the issue which deserves consideration. Some aspects of this other argument draw attention to important qualifications in the "death with dignity" position. First of all it must be admitted that the "naturalness" and "dignity" of death is often more compelling a view to the non-religious than to the Christian. The Christian view is somewhat ambivalent about death. On the one hand death is seen as a punishment for original sin and not at all natural.

But on the other hand, Christians believe in salvation and immortality which should endow death with a dignity and even a certain attraction. Yet as one theologian writes, "How striking it is that those who profess faith in personal survival after biological death are often the ones who hang on most grimly and desperately to biological life in spite of the end of personal integrity."¹⁰³

Part of the answer to that observation comes largely from testimony of the dying themselves and those with most experience with the dying. The answer is simply that while death may be natural, necessary and dignified looked at communally or religiously or from the long range and evolutionary standpoint, the actual individual *experience* of it is more often that of varying degrees of *indignity*. And this includes so-called "natural" death.

Dying can be peaceful, dignified and noble, but this is probably more because of what the dying persons and those who assist them bring to the experience in terms of convictions, insights and empathies than what the experience of itself and by itself provides.

As Elisabeth Kübler-Ross writes, though learning to look at and prepare for death and dying from the right perspective remains

essential and long overdue for most of us, nevertheless, "*It is hard to die, and it will always be so, even when we have learned to accept death as an integral part of life, because dying means giving up life on this earth.*"¹⁰⁴

She and others write of how the dread of death involves for many the fear of oblivion and the loss and separation from all one's loved ones, and one's own self, one's experiences and the possibility of any new experiences in the future. For some the consuming dread includes expected punishment in the after life. For most, fear of death is fear of the unknown. But whatever one's particular reason for fearing death, the fear is there in all of us at one level of consciousness or another, and it may very likely serve a positive function: "Such constant expenditure of psychological energy on the business of preserving life would be impossible if the fear of death were not as constant. The very term 'self-preservation' implies an effort against some form of disintegration; the affective aspect of this is fear, fear of death."¹⁰⁵

In the light of these existential observations it may be both unrealistic and unhelpful to the dying to pretend that "indignity" can ever be fully refined out of the experience of death. "We do not begin to keep human community with the dying if we interpose between them and us most of the current notions of 'death with dignity'. Rather do we draw closer to them if and only if our conception of 'dying with dignity' encompasses — nakedly and without dilution — the final indignity of death itself, whether accepted or raged against."¹⁰⁶

A further qualification of the "death with dignity" thesis deserves attention here. It should not be forgotten either by physicians who use life support systems and treatment, or those who argue against their use, that the primary, original and laudable purpose in their development and use is that of "buying time", so that careful diagnoses and prognoses of the patient's illness can be made.

They were not and (in principle) are not intended to serve as permanent substitutes for all the patient's own vital functions. As such it would be unreasonable to argue that the dignity of all those on life supporting systems is inevitably being violated. Several good medical reasons might justify even the protracted use of such life supporting treatment.

First of all a diagnosis or prognosis might not yet have been completed. Secondly, there may be good reasons to hope for a return of spontaneous functions and consciousness. Thirdly, if the patient is conscious he or she may prefer to fight on even though there are tubes in every orifice and hardly a shred of hope of staving off imminent death. Fourthly, if the patient is in a coma, proxies and attending physicians may believe that the patient indicated before becoming comatose that he or she wanted to be "artificially" supported to the end, no matter what.

In other words, the mere fact of life support systems and their paraphernalia being used need not necessarily imply an indignity to the patient. "Certainly such a state as the one described is not very pretty, nor is it comfortable for any of the parties concerned. But that is not really the issue, unless we let a question of aesthetics rule the issue of life and death. The issue is whether it is undignified for an individual in the throes of death to fight by any means at his disposal. . . ." ¹⁰⁷

In the light of both sides of the "dignity of death" thesis, what is its relevance for or against quality of life considerations?

First of all, none of the views considered above argued that there are no cases where life support systems or treatment constitute an indignity to the patient. It is generally agreed that there are cases which can constitute an unnecessarily undignified dying, particularly when the treatment involves discomfort, offers no hope of even a minimal recovery, is no longer serving its diagnostic function, and the patient has not requested it. This point was forcibly made by the theologian Karl Barth, one of the strongest defenders of the sanctity of life. He wondered whether, ". . . This kind of artificial prolongation of life does not amount to human arrogance in the opposite direction, whether the fulfillment of medical duty does not threaten to become fanaticism, reason folly, and the required assisting of human life a forbidden torturing of it." ¹⁰⁸

Secondly, the mere removal and withdrawal of tubes and respirators does not in itself effect a "death with dignity". The final indignity of dying and death itself remains. It would probably be more accurate to speak of such patients as "dying with *less indignity*". If there is to be dignity it will be because the conscious patient, hopefully now less encumbered, more accessible and able to communicate is assisted and comforted by others in dying.

Thirdly, the brief analysis of the "death with dignity" concept reaffirms the centrality of the "benefit to patient" criterion in such

quality of life considerations. Only a reasonable application of that criterion, ideally by the patient himself or herself, or by the reasonable judgment of proxies if the patient is incapable of making a choice, can determine how the patient's interest, wishes or "dignity" would be best served in a given instance.

In one case patient benefit may best be served by an unsupported but more comfortable last few hours in a terminal illness; or in another case by continuing to fight against death until the last moment with all the medical hardware and software available; or in still another case, by coming to a decision that though death is not imminent, the likely condition or quality of life on recovery will not be sufficient to justify continuation of treatment now.

E. Conclusions: Equal Lives and Objective Criteria

(1) The indeterminate sanctity of life principle alone cannot be used to determine in advance all treatment decisions, without consideration as well of the quality of the lives in question. To do so would be to use that principle as a "decision-avoiding" not a "decision-making" guide.

(2) The meaning of quality of life in the medical context need not mean wholly subjective judgments about the relative worth, value, utility or equality of the lives of persons. Purged of connotations of "relative worth" or "social utility", the function of quality of life thinking in this context (as in the environmental context) can be one of improving and benefiting the patient, and can focus on objective criteria and needs.

(3) In particular there are two such quality of life criteria relevant to decisions to treat, or to continue treatment or to stop treatment. The first considers the capacity to experience, to relate. The second considers the intensity and susceptibility to control of the patient's pain and suffering. If despite treatment there is not and cannot be even a minimal capacity to experience, and to relate, or if the level of pain and suffering will be prolonged, excruciating and intractable, then a decision to cease or not initiate treatment (of for instance a comatose patient) can be preferable to treatment. (See next two chapters for more on these criteria.)

(4) The word "life" can mean two things in this context. It can mean vital or metabolic processes alone, a life incapable of experiencing or communicating and one which therefore could be called "human biological life". Or it could mean a level or quality of life which includes *both* metabolic functions and at least a minimal capacity to experience or communicate, which together could be called "human personal life".

(5) Those with whole brain death are dead as persons, even if biological life (alone) can be maintained externally. It could be convincingly argued as well that those who are (only) cerebrally dead are also dead as persons.

(6) Death is best spoken of as a *single* event occurring when the brain dies. It would be incorrect to say there are different human deaths or that the moment of death is arbitrary even though different cells and organs die at different points on the dying continuum, or because hospitals often are able to "draw out" death and make possible a sort of "technical life" even after real (personal) death has occurred.

(7) If by "life" here is meant personal life, then the use of quality of life language and criteria need not imply or assume *inequality* between lives. All *persons* are equal in value no matter what their condition or quality. But not all lives in the biological sense are of equal value to the patients in question. To cease medical treatment in some of these cases is not unjust discrimination as long as the decision-making focuses on benefit to patient. Death need not always be resisted as if anything is an improvement over death.

(8) Given that the sanctity of life principle imposes the burden of proof on those who would cease to support the lives of others, the consideration of quality of life criteria should not inevitably and exclusively lead to decisions to cease or not initiate life supporting or saving treatment. Quite the opposite should just as often or more often be the case.

(9) While a degree of "indignity" is an inescapable element of death and dying, and while not every instance of a patient's life being externally supported is thereby undignified, there are cases in which the refusal to consider and weigh the patient's quality of life can result in a prolongation of treatment to the point that a real and further indignity is being done.

(10) Both medical decision-making and law should continue to protect the intrinsic sanctity and value of each human life. But medicine (and perhaps law as well) should formally acknowledge that in some cases the quality or conditions of a patient's life can be so damaged and minimal that treatment or further treatment could be a violation precisely of that life's sanctity and value.

(11) Even in those cases for which it is decided to cease or not initiate external life supporting *treatment*, there always remains a continuing obligation no matter how damaged the patient's condition, to provide whatever amount of *care and comfort* is needed and possible.

Knowing who persons are tells us who those are for whom medicine cares. Medicine after all is not merely the enterprise of preserving human life — if that were the case, medicine would confuse human cell cultures with patients who are persons. In fact, a maxim to 'treat patients as persons' presupposes that we do indeed know who the persons are.

— H. T. Engelhardt

Slavery, witch-hunts, and wars have all been justified by their perpetrators on the ground that they thought their victims to be less than fully human.

— Sissela Bok

. . . we need not resolve the difficult question of when life begins. . . the judiciary at this point in the development of man's knowledge, is not in a position to speculate as to the answer.

— Mr. Justice Blackman

. . . when scientists confront value problems, they either hand them over to those who have no compunction in making them, expertly or otherwise; politicians, philosophers, clergymen and pundits of all kinds; or they so disguise them that they pretend to others and themselves that no value judgments have been made.

— Kurt Baier

Chapter 4

Person as a Normative Concept

A comprehensive and detailed analysis of the concept and significance of "person" is well beyond our mandate or needs in this paper (see note 123). Here the much more modest and limited question is this; is a normative concept and definition of "person" in the context of life and death decision making, defensible and useful as a way of incorporating and formalizing some quality of life considerations? Put another way, would we choose the word "person" to describe someone who possesses the minimal criteria for a quality or condition of life that should be preserved? May anyone who is classified as a human but not a person be allowed to die without the ethical stigma involved if he were a person?

Earlier a meaning of "quality" was proposed which attempts to escape the connotation of "relative worth or value". Intended was one of the dictionary meanings of quality, namely "inherent feature", though a consideration was added which can't be considered an "inherent feature", namely the degree and tractability of pain and suffering.

And as an inherent feature of human personal (as opposed to human biological) life, a minimal capacity to experience and to communicate was proposed. Finally it was noted that whole brain death is the only "easy" case if one applies that criterion of "personhood". Easy, because the person is already dead. But, partly because the word "minimal" will always have a degree of relativity and subjectivity to it, it remains a question as to how

justifiable and useful such a definition or inherent feature of person can really be in most other cases.

Some further preliminary remarks may be in order at this point. Some discussions about normative concepts of persons are largely academic and general in content and purpose. This is not the case here in this paper. Here the ultimate and major interest in the subject of person has to do not just with what persons *are* at all, but with what patient-persons may and may not *do*, are and are not *entitled* to, and what may, may not and should *be done* to and for patients as persons. But to talk about what patients as persons may do, how they should be treated and what they are entitled to, logically calls for some prior thinking about what counts as a person.

On the one hand then this paper's primary and ultimate concern, both until now and in the rest of the paper, is with what could be called the ethical principle of *respect for persons*. This principle, closely related to that of the sanctity of life, incorporates especially two convictions. The first is that individual persons should be treated as autonomous agents, and the second is that persons with diminished autonomy are entitled to protection by others. That principle and those convictions should always be central in all biomedical decision-making.¹⁰⁹

But on the other hand, while "respect for persons" as just described does refer to a characteristic of persons ("autonomous agents"), the principle itself does not really clarify or defend that characteristic or a particular meaning for person. In most ethical debate those who refer to or "unpack" the principle, "respect for persons", simply *assume* that we know and agree upon what counts as a person. In some biomedical issues such an assumption may be more justified than in the ones we are considering in this paper. In some issues there is no room for doubt that what we have before us are persons, and the problem becomes immediately that of sorting out the rights, duties and needs which are relevant to "this person", or in dispute between "these persons".

But in other cases it is at least arguable that the first questions should be, what counts as a person, and are we dealing here with persons? These questions seem particularly appropriate in decision-making about abortion, genetic engineering, defective newborns, criteria for determining death and allowing patients to die.

Which is not to say that answering the question about what is to count as a normative "definition" of person is necessarily either

possible or helpful. As we shall see, some say it is neither. Nor would it necessarily follow that because a certain instance of life is not yet, or no longer or never will be a person that therefore it is not entitled to protection in some way and for some other reason. In some cases at least it need only mean that the protection and care extended will be for some other reason than respect for personhood.

Time now therefore to explore the justifications, limitations and applications of "definitions" of person as normative in our quality of life questions.

A. The Difficulties. A "Permissive" or "Protective" Role?

The inherent features or nature of persons is implicitly or explicitly a central concern in most biomedical issues. In principle most of us tend to think that nothing could be more desirable than to determine and make universally normative a fixed definition of human person which would serve as a test for any projects to change, improve, cure or cease to treat humans. But there are some major difficulties and limitations in any such undertaking.

In the first place, there is a lurking suspicion that the very desire and perhaps even real need to find rational answers to such basic questions is provoked not only by the existence of unhealthy people but is itself a symptom of our unhealthy culture. The combination of increasingly "undigested" technological advances in medicine and biology, as well as loss of contact with powerful but unconscious cultural symbols and convictions, has placed an enormous burden on the rational side of life. It is often said or implied that we once knew better than we do, what persons are. Our ancestors knew this (it is said) instinctively, as well as verbally and rationally thanks to the images, rituals and visions of the culture they grew up in. Images and meanings of person, if they are to carry any weight, have any influence, be more than a minority view, must speak to our imagination and feelings as well as to our reason.

In short it is very difficult, some would say impossible, to propose anything very compelling about the nature of man or person in mere verbal formulations. There are those who maintain that even today we know "intuitively" what is most valuable and characteristic about the human person and that to drag reason in, is only

complicating the simple. But if this were really so would it not be easier than it is to find consensus and agreement about what is normative about person?

Secondly, it is not as if a normative "definition" or inherent feature of person is self-evident and can be directly read and determined from empirical data alone. Descriptive definitions of person are difficult enough. It is possible of course to list a number of descriptive characteristics conjunctively. But behind decisions about *what counts as evidence*, what data to select, even for descriptive definitions, undoubtedly lie prejudgments and a priori ethical commitments about what the human person is and is not.

The greater difficulty is in going from descriptive to *normative* definitions. "Normative definitions pose even worse problems, at the very least because any normative description must involve a procedure for deciding what to do with the data provided by descriptive definitions; and no descriptive definition tells us that. To know that man is a rational animal does not tell us, when a decision to act is called for, of what rational behaviour should consist; the same can be said of any other definition of 'man' or 'human'. Philosophically, this is the old issue of how a move is to be made from the 'is' to the 'ought'."¹⁰

Thirdly, the concept and definition of person in bioethical questions tends to serve two quite different, even opposed, functions. Some worry that it serves a too *permissive* function — for those who don't qualify as persons our responsibility and duty is assumed to be not the same as for those who do.

With some reason this function of "person" occasions and should occasion a degree of hesitation if not sometimes rejection. After all, there are many instances in our own times of societies which based or base the denial of rights to its minorities on their being to some degree non-persons, or outside humanity. And that assumption is no doubt behind much of the racist labelling indulged in at times.

The biomedical issue most frequently identified with the "permissive" role of person is that of *abortion*. If it can be shown that the foetus is not, or is not yet a person then it is concluded that medical care and protection can be withdrawn, the foetus may be aborted and (for instance) used as an object of experimentation. In the case of the dying, if it can be demonstrated that a patient is now

a non-person then, since medical treatment and life support is for persons (it is argued), they may be withdrawn.

The objection often made against the "permissive" function of person in these cases, is not that the notion of person is one factor, even the primary factor evaluated in decisions to abort or cease life support, but that it becomes in effect the only factor. Other considerations, such as needs, benefits, wishes, social context and social implications are given little or no weight.

In this so-called permissive function the "definition" of person adopted often tends to be a somewhat static one, adopted with full assurance that it is the only correct one and good for all time. As well, it is sometimes more oriented to "optimal function" than "minimal function".

But the concept of person can have another function as well. For some it serves a *restrictive* or *protective* role as a deontological protection against, for instance, merely utilitarian considerations in decisions to abort the foetus or cease life support systems for the dying. Paul Ramsey for instance insists on the notion of person to guard against allowing the individual patient to be used for the "good of society" or others in experimental medicine, and to anchor his reminder that the physician's first responsibility is to his patient, not to mankind or the patient's family.¹¹¹

In reality the distinction between the "permissive" and "protective" functions of the notion of person is not necessarily a helpful one. Which label one uses for a particular act is largely of course a matter of perception, and of preconceived positions on moral issues. It is not as if some acts in which person is the norm are always and inherently "permissive", and others "protective".

One chooses one's particular label largely in the light of whether one is for or against abortion, euthanasia, allowing to die, etc. Most of those who acknowledge a normative role for "person" would probably be prepared to agree that the *inviolability of the person* be identified as the limiting criterion against all actual or possible dangers of unjust manipulation, violation or intrusion, and that it be the basis of informed consent and most of the other rights and duties in medicine. But whereas those *against* euthanasia and/or abortion would argue that "therefore" euthanasia and abortion are prohibited, those *in favour of* euthanasia and/or abortion would argue that it is sometimes protective of and non-intrusive of the person to permit, or hasten death for humane reasons or to protect the mother's life by aborting a foetus.

Yet there is, in my view, more to be said in favour of the "protective" function of the notion of person. The use of "person" with a protective and limiting emphasis would seem more consistent with the sanctity of life principle than would person used with a permissive stress. That principle is weighted on the side of protecting, preserving and maintaining life without justifying reasons to the contrary.

But time now to go beyond these general observations and look at the specifics. What is proposed by way of definition of person and the appropriateness of using notions of person in life/death decision making?

B. Relevance and Meanings of Person. The Options

Generally speaking one could say there are three options in this regard, each of which I will describe and attempt to evaluate:

- (1) The notion of person is *not at all* appropriate to medical decision making.
- (2) It is *appropriate*, though personhood resides not in stable attributes but in *something else*.
- (3) It is appropriate, and it involves the possession of certain *stable inherent features*.

1. The Notion of Person Not At All Appropriate

The first view maintains that the notion of person is not really relevant to decision making, and its intrusion may even have harmful consequences. One kind of argument maintains that it is not a relevant factor in most actual decision making by patients, family or physician and therefore (by implication) it should not be.

Of its place in abortion decisions it is maintained that, "The question of whether the foetus is or is not a person is almost a theoretical nicety in relation to the kind of questions that most abortion decisions actually involve."¹¹²

And of decisions involving the dying, or involving defective newborns, this view maintains that,

When someone is dying, we seldom decide to treat or not to treat them because they have or have not yet passed some line that makes them a person or non-person. Rather, we care or cease to care for them because they are Uncle Charlie, or my father, or a good friend. In the same manner, we do not care or cease to care for a child born defective because it is or is not a person. Rather, whether or how we decide to care for such a child depends on our attitude toward the having and caring of children, our perception of our role as parents, and how medicine is seen as one form of how care is to be given to children.¹¹³

This argument underlines the difficulty we noted above — it is hard (even impossible insists this view) to find in terms of mere verbal formulations a practical, effective, acceptable definition of person, given that a moral consensus no longer exists. It argues then that a regulatory notion of person does not “work” and cannot.

The argument correctly notes that decision making does, and even must, weigh factors other than just presence or absence of personhood. But it is doubtful whether such arguments have really fully established their case in other respects. True, considerations of personhood might not *actually* play much role (at least not in an articulate and fully explicit manner), but perhaps they can and *should* play a greater role. It may well be impossible to achieve a consensus on a detailed, specific normative definition of person and on *exactly* how much weight to give that definition in decision making.

But it is my contention that that kind of consensus is not even desirable given the space (within morally established parameters) one ought to leave for the various value mixes different people will opt for in these matters. It is also our contention that an acceptable, normative, and morally justifiable “definition” of person can and should be formulated, even though it must remain somewhat general, open to new information and insights, and not the only quality or condition to be weighed.

The other kind of argument maintains that a notion of person used in medical decision making is harmful and dangerous, particularly for the weaker members of society. It is harmful to base protection of life on the possession of humanity or personhood (it is argued), first of all because of the dangerous assumptions involved in doing so.

Some of these are noted by Sissela Bok. The first of these assumptions, “is that humans are not only different from, but *superior* to all other living matter. This is the assumption which

changes the definition of humanity into an evaluative one. It lies at the root of Western religious and social thought, from the Bible and the Aristotelian concept of 'the ladder of nature' all the way to Teilhard de Chardin's view of mankind as close to the intended summit and consummation of the development of living beings."¹¹⁴

The second assumption is that because of our supposed superiority, we are justified in using the non-human as we wish, even killing it. "Neither of these assumptions is self-evident. And the results of acting upon them, upon the bidding to subdue the earth, to subordinate living matter to human needs, are no longer seen by all to be beneficial. The ancient certainties about man's preordained place in the universe are faltering. The supposition that only human beings have rights is no longer regarded as beyond question."¹¹⁵

But the worst danger (Bok argues) in basing normative conclusions on such a distinction is the, "... monumental misuse of the concept of 'humanity' in so many practices of discrimination and atrocity throughout history. Slavery, witch-hunts, and wars have all been justified by their perpetrators on the ground that they thought their victims to be less than fully human. The insane and the criminal have for long periods been deprived of the most basic necessities for similar reasons, and excluded from society."¹¹⁶

The above observations from experience and history are in large part both accurate and significant. We humans *have* arrogantly abused nature largely on the assumption that persons are superior and have that right; we *have* denied rights, ignored needs and neglected to care for minorities and so-called "deviants" on grounds of their not being fully human; we have indeed misused the concept of humanity or personhood, and sad to say we probably always will.

But to cite examples of the historical or actual misuse of the concept of personhood is not really a compelling argument proving that it never can be or never has been well used. At best such examples can and should warn us to be extremely cautious in how that criterion is used.

There are a number of considerations such arguments tend to leave unsaid or unfaced. A deeper inquiry into the cited historical and contemporary examples of the concept's misuse suggests there were, and are, unhealthy dynamics at work at a much deeper and more fundamental level than simply the misuse of a concept. The ignorant, prejudiced, and discriminatory misuse of the concept

"person" would not have succeeded unless the society itself or a powerful political or religious minority were already ignorant, prejudiced and discriminatory.

In at least some instances one suspects that it was not at all the exercise itself of seeking a consensual, explicit and articulated definition of person which led to discrimination and deprivation — it was rather the *not* doing so. It is reasonable to argue that in the absence of at least a generally acceptable and relatively articulated statement about the moral parameters of human person, the vacuum will be readily filled by minority and often fanatical views and fears imposed upon the majority. Witches and the mentally retarded are perhaps cases in point. In both instances fear and confusion in the face of the different and the unknown was the starting point, not definitions of person.

The systematic burning of witches runs like a thread through more than 200 years of the history of Europe, from the decline of the Middle Ages, through the Renaissance, Reformation and Counter-Reformation. However, the roots of the "witch-craze" are deep and complex, and any labelling of witches as "non-human" would only have been a consequence and a branch, not a cause and a root of the real malaise. To a large extent the elaborate and systematic demonology ascribed to witchcraft was not even professed by the so-called witches themselves, but was a powerful myth constructed by a society increasingly intolerant of and unable to assimilate its non-conformists, a society faced with disastrous social ills (the Black Death, the Hundred Years War, the Thirty Years War), and therefore a society in need of scapegoats as well as a reason to crush them. That justification was found not at all in the denial of "humanity" or "personhood" to "witches", but by the inquisitors seeing themselves as worshippers of God, and witches as worshippers of the Devil, plotting the downfall of Christendom.¹¹⁷

As for the mentally retarded, the same human tendency to banish from our midst and label as deviant what we don't understand or don't want is the real source of any tendency to label them as non-persons. But again, using the labels "non-person" or "non-human" (if they are used at all) constitutes the last step, not the first, and they are not at all the only or worst labels used for these people.

Perhaps we will continue to invent, persecute and banish scapegoats for our individual and social ills, but one is at least entitled to hope that the now general acknowledgment that

so-called "witches" were unjustly persecuted (and labelled) as well as the growing recognition in some quarters at least, that we are still doing so to the mentally retarded, points not only to society's increasing tolerance, but also to the evolution towards, and the usefulness of a wide, but normative and protective definition of person even in our pluralist society.

Let me now conclude and sum up my evaluation of the view that the concept of person is inappropriate either because it "won't work" or is positively dangerous.

The concept clearly has been and still is misused in a discriminatory manner. But that fact can also argue *for* not *against* attempts to arrive at at least a general and generally acceptable definition. It is at least possible that the very discriminations and prejudices some rightly ascribe to the application of overly reductionist and permissive criteria of person could best be protected against, not by abandoning all efforts to think about and develop such person oriented criteria, but by increasing such efforts.

If "benefit to patient" becomes the guiding light in both the formulations of the definition and their application to particular cases, then the worst of the abuses against the needs and rights of individuals may be more effectively guarded against. Surely there is more hope to be found in that direction than the alternative — simply throwing up our hands in defeat and trusting intuition on the grounds that mistakes have been made, and probably will continue to be made, in the on-going search for morally acceptable parameters of the notion of "person".

2. The Notion of Person Is Appropriate, but Personhood Need not Reside in Stable Attributes

This second view is arrived at from a number of directions; it attempts to answer a number of related concerns. The approach defies exact categorizing or labelling and does not so much constitute a certain "school" as a certain theme with a number of variations. It often uses words and concepts other than "person" but at least roughly equivalent in intent. I will discuss and consider two of them, both of which arrive at the same conclusion.

The *first* is the desire to extend rights, particularly the "right to life" to those usually excluded from the ranks of moral agents and therefore of person. In such cases this approach substitutes

something else for the stable attributes usually identified as necessary for moral agency and right-claiming, such as rationality, freedom and self-determination. The kind of cases envisaged as meriting this extension of moral agency and personhood are for instance the foetus, newborn infants, the mentally retarded, the mentally ill, the comatose and the senile.

Since in all of those cases there is a temporary or permanent incapacity for self-determination (the foundation of morality and rights such as the right to life), then (it is argued), those not in the moral community, "cannot plausibly be considered moral agents because they are evidently unable to live by rationally adopted rules as morality demands, and therefore the argument does not secure for them a moral right to life. So it is possibly not surprising that at one time or another it has been thought quite permissible to kill them".¹¹⁸

Referring to human "dignity" (and from the context apparently intending "personhood" as well) here is another statement of the same view along with a proposed solution:

People strong enough to claim such recognition of this individuality are already in a way manifesting it. But there are problematic cases where the person is already so menaced or demoralized that no such subjective claim can be made. . . If we try to look for stable attributes of people, in virtue of which they may claim dignity, we are liable to be pursuing a will o' the wisp. Rationality cannot survive senile dementia, self control cannot survive various overwhelming pressures; and the diversity of concrete human capacities and incapacities makes the identifying of a lowest common factor singularly artificial. On the other hand, the same variety makes strongly convincing the *irreplaceability* of anyone. And it seems likely then that it is the being-valued-as-irreplaceable which constitutes anyone's dignity. But this makes dignity essentially a matter of relationship.¹¹⁹

There we have it — the proposed alternative to stable attributes is everyone's "irreplaceability", or "uniqueness" looked at not as a stable though permanent attribute in itself (which it could be as long as life continues), but rather as irreplaceability *to someone else*. That must be what the writer means by adding that dignity (by implication, personhood) is essentially a matter of relationship. The writer underlines this point more emphatically in what follows. Applying this standard to what that writer calls "vegetable children", she writes,

It was quite clear that whatever strains and burdens were involved, the children were, *for their parents*, unique and specific beings. Though permanently incapable of gravity, rationality, self-control, creativity,

they were capable of evoking what sounded more like love than pity, and that somehow was their dignity, whereas, had they been detached from the context of actually being loved, it would have been hard to isolate a basis for it.¹²⁰ [emphasis added]

What is then to count (it is argued) in determining dignity or personhood in these cases is not the presence or absence of intrinsic attributes possessed by the patient or subject, *independently of whether parents and others value and support that subject*; normative in this regard is to be instead the judgment of others as to whether one is or is not unique *to them*.

Out of a laudable desire to articulate a clear moral basis of rights for those not able to claim them themselves, this view has effectively managed to shift the normative emphasis from the subject, to those around the subject. Instead of evaluating the subject's actual or potential ability to relate and communicate with others and derive pleasure from others, we are now to evaluate the ability of others to relate to the subject. But are these subjects really better served by such a criterion of dignity or personhood? Is such a criterion likely to promote the interests and benefit of the subject? We think not. There are two obvious threats or dangers.

On the one hand, assuming that by quality of life and other criteria evaluating the *patient's own* capabilities and other conditions (such as intractable pain and suffering) it is judged to the patient's benefit to continue life support, then a decision to cease treatment in the absence of parents or others who see the child as "irreplaceable" would be to the child's detriment. On the other hand, if it were judged by similar evaluations of the patient's own condition that further treatment would impose an unjustified burden on that patient, it would be equally non-beneficial to the patient for treatment to be continued only because the parents or others derive joy or satisfaction from the patient's continued life.

None of this is to suggest in any way that the greater readiness of parents, health care professionals and society generally, to value and care for the individuality and lives of the defective and dying, ought not to be an urgent priority for all of us. Clearly it should be. And just as clearly, that readiness or non-readiness is an important consideration to be weighed and worried about in individual medical decisions other than life saving and life sustaining ones.

But in these latter it should not be the determinative factor. It should influence decisions about appropriate care and treatment and

whether an institution or the family is best equipped to provide it. But that consideration should not determine decisions to continue or discontinue life support treatments. The likely consequences argue against it.

Nor should the reservations expressed above be taken as a belittling of the claim that if human persons are to evolve in a healthy manner and achieve their full potentiality as unique individuals, it must be done in relationship, in dialogue with others. The claim has very respectable and credible credentials in philosophy, theology and general experience. The personalist tradition for instance, represented especially by Ferdinand Ebner and Martin Buber, has compellingly maintained that man can best be understood and develop as a person in dialogue with other persons, both divine and human. (See note 123 for more on this point.)

But the proponents of the personalist tradition never sought to *displace* other views or traditions which stressed man's rationality and self-determination. They only sought to add other dimensions and balances. In fact the personalist tradition itself emphasized not only that man shapes his personality in dialogue with others, but also that he is autonomous and responsible.

A second direction from which much the same point is made, is one which does not talk directly about person or personhood, but about quality of life. Yet the thrust and meaning is much the same. Here too the emphasis is shifted from evaluating the quality of life of the *individual patient*, to that of the family, the health care professionals or society.

This shift of focus away from the patient's own condition, natural endowments and prognosis, to evaluations of the quality of life (*i.e.* condition and natural endowments) of family or others, tends to take two different forms. By way of example we may take an attempt to weigh the actual and potential quality of life of a seriously defective newborn. One form this evaluation could take is a prediction about how such a child, by way of its own contributions or detractions, will affect other individuals and society generally. In this case what will be weighed are, "Factors such as the contributions the infant will make to the understanding and maturing of his siblings, to what extent he will give pleasure to his parents and other members of the family, the financial burdens of medical care and special education. . . "121

But the other form this evaluation could take considers how by way of contributions or detractions, family and society will *affect the newborn*. In this case what is weighed to determine quality of life is, "... the aptitudes, motivations, skills and pleasure, physical and intellectual, which the individual acquires as a result of efforts made on his behalf by his family and by society."¹²²

Is there a moral difference between the two forms? Some think so, and argue that the second form (actual or potential contributions by the family and others to the patient) is an integral part of that patient's quality of life, and as such deserves to be determinative in decisions to medically support or not support lives.

I do not fully agree — at least not without some further qualification. In my view both forms, insofar as they might allow factors extrinsic to the patient's actual and potential endowments, condition and prognosis to determine such decisions, could suffer from the same shortcomings we already indicated above in the case of similar evaluations of "personhood".

It is of course correct and important to note that quality of life, "may be improved for many individuals with an impaired natural endowment by increasing the contributions of home and/or society."¹²³ After all, the condition or quality of life of a defective newborn or older patient is not necessarily static and unchangeable. As families, physicians and nurses know, a defective newborn's condition which a prognosis at birth might indicate is less than minimal, can sometimes with proper care improve up to or beyond the minimal level. For this reason an important contributor to the quality of life of newborns and other seriously handicapped patients can sometimes be *our* readiness to help and care. Both new learning techniques as well as other medical/technological advances can sometimes strikingly improve the intellectual and sensory perceptions, ability to communicate and ability to be mobile of the seriously retarded or otherwise handicapped patient.

Nor should it be assumed that obtaining accurate and fully reliable diagnoses and prognoses (especially about the extent of brain damage) is always medically possible, particularly in the case of a very recent newborn. Often enough it is only possible some weeks after birth and once life supporting treatment has already been started. It is often difficult to predict with certainty a recent newborn's long range health status, and some defective conditions do sometimes improve markedly with time even without any "extraordinary" treatment.

These latter points impose an important qualification upon what this paper has proposed thus far. It is this. *If and when* an accurate and certain diagnosis and prognosis can be made, *including* a reliable assessment of how both loving care as well as medical or other techniques and aids presently or soon to be available are likely to affect the handicapped patient's ability to function and level of pain and suffering, *then and only then* are families, physicians and others in a position to make ethical decisions to allow or not allow to die. Only if there appears to be no reasonable hope of *loving care* as well as available *treatment* techniques and technology eventually providing at least a minimal capacity to experience and relate, or alleviating excruciating suffering, may one stop or not begin curative or life supportive treatment, and (continuing to provide palliative care) allow the patient to die.

But the mere fact that potentially remedial treatment is not presently available from the newborn's or patient's *family*, should not be determinative in making that decision. To decide against allowing to die, that help need only be available somewhere, from someone or some agency now or in the near future. But what is really determinative is whether this particular handicapped newborn or patient might have or definitely does not have the potential to respond to that care and to develop because of it at least to a minimal level of function and comfort. If the family cannot provide it, that does not mean no one else or no other agency should, and even at considerable expense and burden to society.

If these decisions were to be based upon whether or not a given family were willing or equipped to contribute care and attention to a defective newborn or terminally ill adult, we could be open to some very dangerous consequences and face some insuperable difficulties. For instance: Some (newborn) patients with at least a minimal potential ability to experience and communicate might be allowed to die because here and now there was no one to communicate with; another with a minimal capacity to experience and communicate but facing a life of intractable and excruciating pain and suffering might continue to be supported only because the family is ready to accept the burden of caring for and loving it.¹²⁴

It is difficult enough to evaluate the patient's own inherent qualities, condition and prognosis — how could one evaluate the present and future care and attention available to a newborn or patient from its family with sufficient objectivity and accuracy to use it as a basis for a life or death decision here and now?

The cases envisaged in this section are, of course, those necessitating life and death decision-making *by others*, not by the subject. Such cases are especially newborn infants, the mentally retarded, the comatose and the senile. It will be argued later (in the "Treating and Dying" section), that *competent* patients should be allowed to request cessation of treatment for *any reasons* valid to themselves, including therefore burden on others or lack of home or friends to care for them and help them to develop. For competent patients to refuse life saving or life sustaining treatment for such reasons might well in many cases be both tragic and a terrible commentary on the scarcity of care and compassion in our society — but they nevertheless have that right. But here the point has been that these are not good reasons for or against life saving or sustaining treatment when the decisions have to be made by others for patients unable to give or who did not give any relevant instructions themselves.

There are already those who in principle accept that more objective quality of life criterion (i.e. patient's potential to relate) but worry that, "in practice, however, it may not quite work out that way. More often, our repugnance at the state of others tends to make us believe the other could not possibly relate."¹²⁵ Observations of this kind remind us that medical policy proposals in life and death matters can in practice serve interests other than that of the patient. It is a danger which cannot be lightly dismissed and must be faced and guarded against in formulating policies in this area.

A question directed to some recently promulgated hospital guidelines on the initiation and withdrawal of life support measures is relevant to our concern at this point: "To my mind the most important question is this: At whose good are these new statements aimed? Are they aimed at freeing the patient from the tyranny of a technological (or bureaucratic-professional) imperative to keep alive at all costs, a tyranny that many thinking persons fear as more or less distinct menace to their well-being and liberty in their last days? Or are they aimed at freeing society from the burden and expense of caring for a growing multitude of extravagantly moribund persons?"¹²⁶

There is, finally, a particular issue and practice which raises the same kind of question though from a different perspective. And because the attitudes, practices and implications in question are too seldom discussed and examined, there is an increasingly urgent need to do so. The issue is that of abortion for genetic or other foetal defects.

Until recently the major question in this issue revolved around whether the mother had the right to abort in such cases for the benefit of the foetus, the mother and perhaps the immediate family. But there is a shift in emphasis both in ethical debate and social policy proposals. "There are an increasing number who would argue that even if an individual couple is willing to run the risk of bringing a defective child into the world, and to bear the psychological burden of caring for it, it would nonetheless be antisocial for them to do so."¹²⁷

It may well be that in some circumstances the right to procreate is not absolute and unlimited. But it is one thing to argue that for the purpose of population control (for instance), a society may have the right to limit the number of children a couple should have, and quite another thing for a government to impose regulations about the genetic quality of the children allowed to be born. There are of course ethical problems with population control policies, and in that kind of proposal there may be some discrimination against some *parents*, but not against any individual potential children.

I do not argue that parents should be forced to bear defective children — only that they should have the right to do so. "If an affected person has a right to be born and to live, then this right cannot be set aside simply on the grounds that the child will cause the parents to suffer; it has not been part of our tradition to deprive others of life because of the burdens they impose on those around them. Moreover, it has increasingly been thought the function of government to protect lives and, through use of the power of taxation, to raise such funds as may be necessary to support those whose lives are disadvantaged."¹²⁸

If parents should be allowed the option (but not under "social duress") to abort a child known by foetal examination techniques to be defective, then the major justification will normally be not simply the expected parental burden of rearing that child, but that it is for the benefit of the foetus which would otherwise face a life of great suffering and severe limitations. That may or may not make the act immoral, depending upon whether or not the foetus is viewed as a human person with a right to life, and if it is, whether or not abortion in such a case respects or violates that right. But it may be based on a mistake in prognosis. In other words, it is by no means established that all children with certain defects, for instance Down's Syndrome, will suffer to any great extent. In fact the contrary is probably more often the case. Most Down's Syndrome children can

be reasonably happy, can give and accept love, and are sufficiently intelligent to handle simple jobs.

Of course the previous statement would be both naïve and callous if one did not hasten to repeat again that such children can be and do those things to the level of their full potentiality only if there are in fact loving and caring people living and working with them. Which leads to the observation that too many of those who oppose the abortion of certainly and seriously handicapped fetuses give little or no thought to the question of who will care for them after birth if the parents become unwilling or unable to do so. If society is to allow parents the right to decide whether or not to abort affected children then neither that parental right to decide nor the right of the defective newborn to protection and care are meaningful unless society is prepared if necessary to provide part or all the needed care and love.

3. The Notion of Person is Normative and Useful, and Involves the Possession of Stable Attributes

We come now to the third proposal or view, the one which, qualified in a number of respects as I shall later do, appears to me the most tenable in decision making about initiating, continuing and ceasing life support treatment, as well as decision making in other biomedical issues.

(a) *The foetus as person*

The notion of person (or "human", but meaning "person") understood as normative and referring to intrinsic capacities and attributes, plays a central role in discussions and arguments about the personhood of the foetus, and about abortion. In that context "person" or "humanity" is often simply claimed to be present at a certain stage; much less often is the operative notion of person described and defended.

Nor is the argument usually about the biological or other factual data as such. Generally speaking there is agreement about what is known about the biological/physical development of foetal life. The arguments about when personhood or humanity begins, and therefore merits protection, are more questions of differences in a priori views and convictions about life, than about biological or other data. The differences are about the interpretation of the data, and, "about the names and moral consequences we attach to the changes in this development and the distinctions we consider important."¹²⁹

Theology, philosophy and law have all attempted to deal with abortion by wrestling with the question of when (if ever) before birth there is a human person. Various moments have been, still are (and probably always will be) proposed. Some argue that the human person is present from *conception* on, based largely on a claim on genetic grounds that potential human personal life is equivalent to actual personal life. Others argue that the moment is the *implantation* of the fertilized egg, some 5-7 days after conception.

Others claim the moment is when the foetus begins to *look like a human*, sometime about the 6-week period. Still another proposed moment is that of the *quickenings* of the foetus, when the mother first feels the foetus moving. Others claim it is when the foetus becomes *viable*, that is, capable of living apart from the mother, after about the twentieth week of gestation.

The U.S. Supreme Court abortion decision is a case in point. Without actually stating when they believe human (personal) life actually begins, the Court asserted that from the time of *viability* the State has a "compelling" interest in protecting "potential" life. It is interesting to note how casually Mr. Justice Blackman in delivering that judgment (*Roe v. Wade*) bypassed the critical question of when human life begins. He merely noted that,

... we need not resolve the difficult question of when life begins. When those trained in the respective disciplines of medicine, philosophy and theology are unable to arrive at any consensus, the judiciary, at this point in the development of man's knowledge, is not in a position to speculate as to the answer.

The same issue of when personhood begins was also carefully avoided in the somewhat parallel Canadian decision, *Morganthaler v. The Queen*. In the preface of his opinion Mr. Justice Dickson noted that,

It seems to me to be of importance, at the outset, to indicate what the Court is called upon to decide in this appeal and, equally important, what it has not been called upon to decide. It has not been called upon to decide, or even to enter, the loud and continuous public debate on abortion which has been going on in this country between, at the two extremes, (i) those who would have abortion regarded in law as an act purely personal and private. . . and (ii) those who speak in terms of moral absolutes and, for religious or other reasons, regard an induced abortion and destruction of a foetus, viable or not, as destruction of human life and tantamount to murder. The values we must accept for purposes of this appeal are those expressed by Parliament which holds the view that the desire of a woman to be relieved of her pregnancy is not, of itself, justification for performing an abortion.¹³⁰

Others will argue that the moment of personhood is when there is a sufficiently developed *nervous system* to constitute potential for self-awareness. And, finally, some maintain that it is the moment of *birth* itself at which foetal life becomes personal life.

As for the law, generally speaking one is only fully recognized as person in the full sense after birth. This is the position of the U.S. Supreme Court. In Canada that position is articulated in several sections of the *Criminal Code*, the clearest statement being that, "A child becomes a human being within the meaning of this Act when it has completely proceeded in a living state from the body of its mother. . ." [Section 206(1)]

But this does not mean an unborn child has no rights in law. Though not considered a "legal person" in the full sense before birth, it is noteworthy that courts in many jurisdictions, including Canada, allow the recovery of damages for injuries caused to them before birth. It may not be entirely logical especially since no right to the logically prior "right to life" of an unborn child is recognized,¹³¹ but whether "formally" considered person or not, a number of cases, statutes and articles suggest that the injured foetus is at least to this extent treated as if a person.¹³²

Of course for the law merely to recognize an obligation upon others not to harm a foetus, does not necessarily imply that the foetus "personally" has the right to protection (it could be the mother's or family's right), or that the foetus therefore has all the other rights of a person, or has personhood itself. Studying and deciding these points in detail from a legal perspective is a task for others. But we can at least conclude that in law there sometimes seems to be a certain "as if person" ascribed to the foetus itself in some respects and for some purposes.

It is not our purpose to attempt to discuss and debate the many views about person in the context of abortion. That is a massive and almost insuperable task in itself. But there is at least one point of direct relevance to our interests. Even though some of the "person and abortion" discussion in theology and philosophy does not attempt to define or describe person, and even though there is no definition at all in law,¹³³ all three disciplines and all the many views we outlined above nevertheless usually determine the presence or absence of personhood largely on the basis of some stable attributes or capacities possessed or potentially possessed by the life in question.

This is not to claim that there is general agreement about when exactly they become present (if ever), or what terms to use for the attributes, or whether "potential" persons qualify as persons, or what reasons or rights of other persons might outweigh the rights of the foetus before or after achieving "personhood", or that everyone feels an appeal to person is relevant.

But at least there is a certain consistency and agreement (among those who feel person is relevant) in the questions asked, and in the conviction or intuition that the central question has to do with personhood, and that the attributes which constitute it are the actual or potential capacity for functions variously referred to as self-awareness, consciousness, rationality, self-consciousness, freedom, communication, etc.

These attributes often overlap, and some argue that just one or another of them is sufficient. Some insist that at the moment of conception all these functions are potentially present genetically and that (therefore) potential persons are in fact persons, with all the rights of persons. Others disagree and maintain that a foetus only moves from potential person without rights to actual person with rights, when the anchor of moral prerogatives and rights becomes present in the foetus' biological constitution. That anchor or "fundamentum" (it is argued) is the constitutive potential for self-awareness, the applicable criterion of which is the presence of a nervous system complete in its basic cellular structure, though not necessarily yet fully developed as in adults.¹³⁴ In this view and according to this criterion a foetus would become a person possibly at four months and certainly by seven months.

In my view this latter position is more compelling than the previous which identifies actual personhood with potential personhood based on genetics.¹³⁵ But my real point here is only that both of these views, and the others, tend to consider as normative of personhood (and rights) similar stable attributes of foetal life. The attributes are in fact similar in substance to the ones I and others propose as normative at other stages in life when faced with treatment decisions, namely a minimal capacity (at least potentially) to experience and to relate.

It is perhaps noteworthy that even in many abortion arguments and views which claim to reject personhood as a relevant consideration, or simply leave it undefined, there is still at least an *implicit* (and perhaps unconscious) acceptance of the normative value of substantially these same attributes. For instance Sissela Bok who

thinks we should abandon a quest for a definition of humanity, offers the following reasons as to why the foetus in its earliest period does not require protection: "This group of cells cannot feel the anguish or *pain* connected with death, nor can it fear death. Its *experiencing* of life has not yet begun; it is not yet *conscious* of the interruption of life nor of the loss of anything it has come to value in life, nor is it tied by *bonds of affection* to others [emphasis added]".¹³⁶

It is difficult to see any real difference between what Bok considers normative and what I am proposing as the stable attributes or inherent features of personhood — ability to experience and to relate. And presumably Bok is implying above that when at some later stage these capacities are in fact present, there will be reason to protect those lives. Bok may believe this is not talking about human personal life — in my view it is.

Let us turn now from "person" in the context of the foetus, to "person" in the context of primary interest to us — human life after birth. What stable attributes or inherent features are proposed, how can we justify our choice, and how is our criterion to be used in practice?

(b) *Criteria for optimal existence?*

A number of scientists, ethicists and others have proposed person criteria or definitions which could best be described as criteria for "the good life" or the "ideal life".¹³⁷ Examples are for instance, "the desire to satisfy curiosity", and "the desire to feel meaningfully related to the world and others." But my interest is in *minimal* criteria, not criteria for *optimal* existence. The further we stray from minimal criteria or definitions the greater the risk of more subjectivity and relativity in decision making. One approach in particular merits our brief consideration here as somewhat typical of the many concerned more with "optimal" rather than "minimal" human life.

The approach is that of the ethicist Joseph Fletcher. His proposal was made in two stages, the first in 1972, and the second in 1974.¹³⁸ In a somewhat tentative manner he first of all proposed 15 criteria or indicators of human or person, suggesting that one of them was a cardinal indicator on which all the others were hinged. He also proposed five "negative propositions".

His "positive indicators" were the following:

- minimal intelligence
- self-awareness
- self-control
- a sense of time
- a sense of futurity
- a sense of the past
- the capability to relate to others
- concern for others
- communication
- control of existence
- curiosity
- change and changeability
- balance of rationality and feeling
- idiosyncrasy
- neo-cortical function (the one on which all the others are hinged — "Without the synthesizing function of the cerebral cortex, the *person* is non-existent".)

His four "negative criteria" are these:

- Man is not non- or anti-artificial.
- Man is not essentially parental.
- Man is not essentially sexual.
- Man is not a "bundle of rights" ("all rights may be set aside if human *need* requires it.").

In a second stage, in 1974, Fletcher reports on the reactions he received, in the form of the four different traits nominated as

contenders for the single, cardinal trait of personhood on which all the others depend, and which would cover all cases. They are:

- self-awareness, or
- the capacity to relate to others, or
- happiness, or
- neocortical function (which remains Fletcher's choice).

Though Fletcher's criteria were meant to be somewhat tentative, they occasioned a great deal of opposition, much of it in my view richly deserved. First of all, most of the criteria are really indicators of the "good life", the "optimal" life, the "mature" life rather than criteria of human personal life per se.

Secondly, it would be impossible to use most of them as "operational criteria". What sort of empirical data or tests would one use to establish with any exactitude or objectivity that someone has for instance "a sense of futurity", or "curiosity", or "self control"?

Thirdly, there is an excessive stress on rationality, on intelligence. Even apart from the fact that I.Q. tests are increasingly recognized as uncertain and non-objective, it seems excessively arbitrary and demanding to state as he does that, "Any individual of the species homo sapiens who falls below the I.Q. 40 mark in a Stanford-Binet test. . . is questionably a person; below the 20 mark not a person".¹³⁹

Should such a criterion ever become normative, many of the mentally retarded and the senile now receiving care and often able to function, albeit in a much reduced and often minimal manner, would be excluded. What weakens if not disqualifies Fletcher's case on this issue of intelligence (and some of his other points) is the flavour of permissiveness or reductionism with which he colours his proposal. A proposal which so casually excludes so many from qualifying as human persons does not seem consistent with a respect for the sanctity of life.

He has a tendency to refer to complex issues admitting of great variety as if they were simple and univocal, particularly on this issue of intelligence. For instance he writes elsewhere, "True guilt arises only from an offence against a person, and a Down's is not a

person".¹⁴⁰ By Fletcher's criterion perhaps not, but as we have already noted, children with Down's syndrome in fact cover an enormous range of intelligence and function levels, most of them capable of happiness, communication and at least simple tasks; and many are only minimally defective.

Fourthly, Fletcher neither distinguishes between the criteria which are *necessary* and those which are *sufficient* to determine personhood, nor does he suggest any way of ranking the criteria in order of importance. Finally, Fletcher appears not to give any attention or weight to quality of life factors other than existence or non-existence of personhood. Assuming that his criteria are proposed to aid in practical life and death decision making (as they are), the inherent capacity or physical/biological basis for personhood is simply not the only factor or quality to be considered.

As stated already, the presence of serious and intractable pain and suffering is another. The reasonable judgment and wishes of the patient or proxies relevant to further treatment or life support is another. And an overall focus on benefit to the patient is still another. It is not that Fletcher necessarily excludes these points. But in not even referring to them, much less attempting to integrate them into or relate them to his proposal, he effectively isolates the issue of personhood from the wider complex of concerns and qualities which must also be weighed at the same time.

And yet there is something to be said in Fletcher's defence as well. He did open up an important and necessary debate on a central topic, and he did encourage others as well to seek more specificity in the working criteria of personhood. And at least some of the criteria he proposed refer to stable attributes or inherent features of the life in question, rather than to circumstances and qualities outside and apart from it.

And finally one is inclined to agree with him that the criterion he proposes as the "hinge" of the others, namely neo cortical function, is indeed that. Our choice as the primary indicator of personhood, namely a minimal capacity to experience and relate, would be impossible without a functioning neocortex. Neocortical function alone may not always be a *sufficient* criterion or reason to continue life support, but it is at least a *necessary* one.

(c) *Person as a moral agent*

There is yet another approach equally insistent upon stable attributes, rather than extrinsic circumstances, as the indicators of

personhood. But this second approach does not propose any *single*, essential attribute as indicator. Rather it proposes more than one trait, though not all the views taking this approach agree upon exactly what those traits are.

One such view is based largely on the deontological ethics of Kant, and argues that only rational, self aware, free human beings can have absolute value, or dignity and thus have rights. Things and animals, because not capable of acting responsibly have only value, not dignity. "Anything that has only value can be replaced by something of equivalent value. But persons, in virtue of being self-conscious, have dignity. That is, they are ends in themselves and as such are not to be compared in value with anything. Persons have an absolute value; things do not. . . . Insofar as we identify persons with moral agents, we thus exclude from the range of the concept 'person' those entities which are not self-conscious, free agents. Which is to say only those beings that are bearers of rights and duties, that can both claim to be acknowledged as having a dignity beyond a value (*i.e.*, as being ends in themselves), and that can be said to have duties (thus be responsible for their actions), will count as person. Of course, the strict sense of person is not unlike that often used in the law."¹⁴¹

It is on the basis of these distinctions that we can distinguish between human *biological* life and human *personal* life, a distinction referred to earlier in the paper. And that distinction in turn provides more clarity about what kind of life specifically and especially the sanctity of life principle (applied to humans) is promoting. "Probably much that is associated with arguments concerning the sanctity of life really refers to the dignity of the life of persons. In any event it surely follows that there is no unambiguous sense of being simply 'pro-life' — one must decide what sort of life one wishes to defend."¹⁴²

On the basis of the same distinctions, one is also able to argue that because cerebral brain life is a necessary condition for the possibility of humanly acting and experiencing, once the cerebrum is dead, so is the person. The life remaining after brain death is an instance of human biological life, not human personal life.

So while this view does insist upon three of the univocal definitions reported by Fletcher — self consciousness, ability to relate and cerebral functions — it does in a certain sense put its stress on the same indicator Fletcher opts for as the essential one — cerebral function: ". . . for a person to be embodied and present in

the world he must be conscious in it. . . The brain is the singular focus of the embodiment of the mind and in its absence man as a person is absent."¹⁴³

The arguments to this point are helpful and convincing. But applying the criteria, who specifically are "persons"? And if "non-persons" do not have rights, but only "value", what does that mean, and what grounds are there if any, in such a scheme of things for protecting a life which may not be readily classifiable as person? After all, one is hesitant to conclude that lives should be put at a risk only because they cannot claim rights as moral agents. What of newborns and children, particularly defective newborns? What of the senile and the comatose?

However compelling the above distinctions and arguments, is there not a deep intuition in us, arguing that at least some instances of human life unable to be responsible or claim rights ought to be supportable and protectable, whether they fit the definition of persons or not? Until now at least this conviction or at least intuition has been reflected in our laws, social institutions and traditions which, generally speaking, extend more, not less protection to the weaker members of society. But it is sometimes argued that one may fairly readily employ "positive or negative euthanasia" for defective newborns on grounds that children are not yet persons.¹⁴⁴

But some others (including this writer) do not share this latter position and are of the opinion that the distinction between the "value" of human biological life and the "dignity" of human personal life does not in itself answer all our questions and may even be applied against our intuitions.

To guard against running too far with that distinction, one should further refine it by proposing (at least) two concepts of person. There is person in the *strict sense* a concept applicable to normal adult humans as moral agents, that is, bearers of rights and duties able to claim rights and have them respected. But there is need and legitimacy for a second concept of person for some other cases — that of person in the *less than strict sense*, what could be called a "social" concept of person. An example is that of the child in the parent-child relationship, in which the child is *treated* as person though it is not one strictly.

The child is not yet a responsible moral agent, yet is in many fundamental respects treated as if person — in various ways it expresses needs and desires for food, care and attention, and they

are responded to. The infant is placed in a social structure, is able to engage in a minimum of interaction and is thus "socialized" into becoming a child and then a person in the strict sense. In other words, even a minimum of social interaction, a minimum of ability to play the role "person" and act like person is sufficient to apply the term person to them and impute to them the rights of a person.

To protect children and others in a similar state by applying the "social" concept of person is a way of expressing the way we value them, a way of making our commitment to them more secure, and indirectly a way of fostering and protecting the value of all persons. Good child rearing in effect demands that if an infant is to become a normal adult (a person in the strict sense) it should from infancy be treated *as if* a person.

With this twofold concept of person one is able to maintain the centrality of the dignity of persons, and the distinction between human biological and human personal life, yet value highly and protect vigorously, some though not all instances of less than (strictly) personal human life. One such instance is that of the defective newborn. Just because they may not be, and may never be, persons in the strict sense, does not mean they do not have great value and sanctity and are unworthy of protection. There may in some instances be *other reasons* arguing in their interests and for their benefit for the non-initiation or cessation of life supporting treatment; but if there is or might be a minimum of potential capacity to experience and to relate, then the mere present absence of personhood in the full strict sense cannot be one of those justifying reasons.

C. Conclusions: Respecting Persons and Determining Personhood

Time now to draw some conclusions from our considerations of person as a normative concept in the context of quality of life considerations.

(1) The ultimate concern in these matters must be with what patients as persons may *do*, and what may or should be *done* to and for patients as persons. In other words the ethical principle of *respect for persons* from a practical point of view is a more important concern than *what counts as a person*. But in the kind of biomedical issues faced in this paper, there is a need to do some

prior thinking about whether and when we are in fact faced with persons.

(2) A normative definition of person encompassing stable attributes or inherent features for use in decisions to initiate, continue or discontinue treatment is both *possible and desirable*. In that such a definition focuses attention on the *patient's* condition and benefit, it can serve as a defence against largely utilitarian considerations raised in the interests and for the benefit of others. It would for instance encourage decision-makers to weigh primarily the patient's ability to relate, not our ability to relate to the patient.

The normative use of such a definition would promote a clear distinction between objective factors intrinsic to the newborn's or patient's actual and potential condition, and the more subjective extrinsic factors more indicative of the quality of life of the family or others than of the patient. The latter factors though extremely important and deserving of attention ought not to have a normative influence in deciding whether or not to treat.

(3) The determinative place in any such definition should be given to a minimal potential capacity to *experience and relate*. Both human experience and religious belief have long and (in my view) indisputably argued that the meaning and purpose of life is found in relating with others (religion would add, with God, as well). At the same time such a "definition" is clearly a *minimal* one, and it should not be understood as an exhaustive or sufficient statement of what a person is. Person is more than capacities or qualities limited by time and space; it is a transcendent concept and not merely an empirical one.

In some cases the application of this "person criterion" will encourage a decision to initiate or prolong treatment, if it offers hope of an improvement, continuation or recovery of the capacity to experience and relate. In view of the significance of that capacity, that decision in those circumstances would be to the patient's benefit. But in other cases the application of the criterion will encourage a decision *not* to initiate or continue treatment because there is no such hope, and therefore no benefit to the patient in starting or continuing that treatment.

(4) The determination of personhood is the central quality of life consideration *but not the only one*. There are others, and all the quality of life factors should be weighed and balanced together in the same decision, not in isolation. One such condition distinct from

consideration of personhood yet related to it is that of the presence of *severe and intractable pain or suffering*. Even in the presence of personhood, the prospect of the serious and continuing burden of such pain and suffering either caused by the treatment or unresponsive to it, when there is no hope of recovery, becomes a moral justification (though never of course against the patient's wishes) for ceasing life support treatment. Severe and intractable pain after all can so isolate, absorb and diminish a person that even though there remains a biological or physical capacity to relate, it becomes and remains in practice impossible for that person to do so, or for others to reach them. Such pain is related to personhood in that it can so "depersonalize" its subject that for all intents and purposes they are inaccessible even to care and comfort.

(5) No decisions to allow to die on the basis of a lack of a minimal potential capacity to experience and relate, or on the basis of prolonged, excruciating and intractable pain, should be made until and unless accurate and reliable diagnoses and prognoses have been arrived at. These diagnoses and prognoses should assess among other things the likelihood of future improvement, and the likelihood that the patient's "below minimum" capacity, or prolonged and excruciating pain and suffering, might respond to loving care and new medical or other techniques and technology either now available or soon to be available.

If there is any reasonable hope of thereby bringing the patient's capacities up to at least a minimal level, or of controlling excruciating and prolonged pain and suffering, then other individuals (not necessarily the family) and society should be willing to bear considerable expense and burden to provide the necessary care and other aids to intellectual and sensory perception, ability to relate, and ability to be mobile.

(6) A "definition" of person may in practice be more of an *indicator* or *guideline* in this context than a strict definition always applicable in one clear, predetermined manner. It is difficult to avoid that conclusion when one considers the "givens" and complexities of actual treatment decisions in life and death situations. For instance: "minimum" in the criterion, "minimum potential capacity to experience and relate", remains somewhat relative no matter how hard one tries to be objective; there remain other quality of life considerations; no two medical cases are exactly alike, each has some more or less unique combination of particulars; different patients (if competent) in distinct but similar cases will (and should

be allowed to) weigh similar factors differently and arrive at different wishes for themselves.

On this latter point for instance, of two competent terminally ill patients, one may choose to have treatment ceased in the interest of less pain, though the result will be shorter life, less self-control and self-awareness. But the other may choose the opposite course.

But to speak of the concept of person as a guideline or indicator is by no means to suggest that its determination be a minor matter, or that decision makers are free to rank its importance and priority anywhere they wish relevant to other factors, or even leave it out altogether. On the contrary, as I have attempted to establish, it is the *central* consideration, not always decisive perhaps, but very often that as well. Whether it be called a definition, a guideline or an indicator, the determination of a minimum capacity to experience and relate should always be considered the indispensable and most important quality of life norm.

Like all other major rituals of industrial society, medicine in practice takes the form of a game. The chief function of the physician becomes that of an umpire. . . The rules, of course, forbid leaving the game and dying in any fashion which has not been specified by the umpire. . .

— Ivan Illich

Thou shalt have one God only; who would be at the expense of two? No graven images may be worshipped, except the currency. . . Thou shalt not kill, but need'st not strive officiously to keep alive. . .

— A. H. Clough

The function of morality in medicine is no longer simply to protect the weak and the sick from indifference or venality, but to protect them also from mercy grown overwhelming by technological advance.

— Eric Cassell

In general terms [medicine] is to do away with the sufferings of the sick, to lessen the violence of their diseases, and to refuse to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless.

— Hippocrates

Mankind are the greater gainers by suffering each other to live as seems good to themselves than by compelling each to live as seems good to the rest. Though this doctrine is anything but new, and to some persons may have the air of a truism, there is no doctrine which stands more directly opposed to the general tendency of existing opinion and practice.

— John Stuart Mill

Chapter 5

Treating and Dying

A. "Ordinary Means", or "Reasonable Treatment"?

We will now move on to an examination of the issue of "ordinary/extraordinary" means of medical treatment. This more traditional criterion is often proposed as a better alternative to quality of life criteria, especially because (it is argued), it deals with more "objective" indications. That being so, a weighing of the merits and demerits of that approach, one which we will find deficient in a number of respects, should help to clarify and make more concrete some of the distinctions and points already made.

1. The meanings of "Ordinary/Extraordinary"

Proponents of the "means" tradition generally argue that it focuses on *objective* factors, whereas quality of life criteria focus on *subjective* factors. Leonard Weber for instance states that: "The emphasis on the nature and consequences of the means used provides for some protection against an arbitrary decision being made on the basis of a judgment about the worth of a particular type of life. . . The focus on means is a constant reminder that we should not decide who should live or die on the basis of the worth of someone's life."¹⁴⁵

And Paul Ramsey even though he argues for the abandonment of the "means" language, yet is still somewhat hesitant to jettison it completely, and on grounds similar to Weber's. He writes, "The terms 'ordinary/extraordinary' — however cumbersome, opaque and unilluminating — directed the attention of physicians, patients, family, clergymen and moralists to *objective* considerations in the patient's condition and in the armamentarium of medicine's remedies. . . ." ¹⁴⁶

Earlier in the paper it was already argued that quality of life criteria need not, and should not, focus on the "relative worth" of lives as Weber implies above that they do. The further point here and now will be twofold. First of all that "means" criteria themselves are extremely relative, vague and inconsistently used in both literature and practice. Secondly that in the final analysis behind and within decisions applying the "means" approach, whether acknowledged or not and whatever the vocabulary used, lies the consideration of the "kind" or "quality" of life effected by treatment. In other words, on the one hand the "means" approach itself can be less objective and illuminating than the quality of life approach, and on the other hand, quality of life considerations are difficult if not impossible to avoid in actual decision-making.

The meaning (or better "meanings") and vagueness of the expression "ordinary/extraordinary means" can first of all be seen in the variety of formulations it has been given in recent years. Certainly the most influential formulation was that of Pope Pius XII when he wrote (in 1957) the following:

But normally one is held to use only ordinary means — according to circumstances of persons, places, times and culture — that is to say, means that do not involve any grave burden for oneself or another. A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult. . . . ¹⁴⁷

Gradually, though with variations in wording, the "means" approach has been incorporated into various codes and directives, both religious and medical. Among them are the following:

The Medico-Moral Guide of Canadian (Roman Catholic) Bishops (1970):

(Art. 9) "every human being has a right to live, and every effort should be made to protect that right.

(Art. 10) However, man is not bound to have recourse to every means to prolong life. Neither the patient nor the doctor is obligated to resort to *involved techniques* for artificial survival."¹⁴⁸

Ethical and Religious Directives for (U.S.) Catholic Health Facilities (1971):

(Art. 28) "Euthanasia ('mercy killing') in all its forms is forbidden. The failure to supply the *ordinary* means of preserving life is equivalent to euthanasia. However, neither the physician nor the patient is obligated to the use of *extraordinary* means."¹⁴⁹

American Medical Association (1973):

The cessation of the employment of *extraordinary means* to prolong the life of the body when there is irrefutable evidence that death is imminent is the decision of the patient and/or his immediate family.¹⁵⁰

Canadian Medical Association (1975):

(Art. 18) "An ethical physician will allow death to occur with dignity and comfort when death of the body appears to be inevitable;

(Art. 19) An ethical physician may support the body when clinical death of the brain has occurred, but need not prolong life by *unusual or heroic means*."¹⁵¹

What all these citations seem to be saying is that there are some means of treatment which are always ordinary, and others always extraordinary. If the former, then it is obligatory that they be used, if the latter there is no such obligation. What appears to make one treatment ordinary and another extraordinary is of course not just *frequency of usage*, but (according to the Pope's statement for instance), "circumstances of person, places, times and culture." Or as a moral theologian put it, what is extraordinary treatment is, "... whatever here and now is very costly or very unusual, or very painful or very difficult or very dangerous."¹⁵²

In other words the distinguishing criterion between them seems to be *usualness*. The focus is on the "usualness" of the treatment, rather than on the condition or quality of the patient's illness or capacities. With a degree of over-simplification one could say that that is the essential difference between the "means" approach and the "quality of life" approach. The crucial factor in the former is the usualness or status quo of the treatment; but the crucial factor in the latter is the condition and prognosis of the patient, which then conditions whether treatment is to be considered ordinary or extraordinary.

In my view Robert Veatch has shed the most light on this subject in recent times, providing both a compelling refutation of the "means" approach (as inadequate, more than wrong), and a convincing case for its replacement by a combination of the quality of life approach and the formal criterion of the "judgment of reasonable people".¹⁵³

The scene can best be set by noting the question Veatch sets out to answer: "Those who decide that the heroin overdose patient is alive, and who also decide that they are opposed to actively hastening death must finally face the crucial moral question: when, if ever, is it moral to cease treatment? Does it make any difference whether a dying patient refuses radical experimental surgery, an expensive but not experimental cardiac valve operation, a mechanical respirator, or an intravenous feeding? Does it make any difference whether the patient is in the last hours of severely metastasized cancer or the early days of a certainly fatal but not presently debilitating disease, in the prime of life or over the hill?"¹⁵⁴

He suggests that it is difficult to find any clear answers to those questions in the "means" approach because the terms "ordinary" and "extraordinary" have three related yet fundamentally different uses:

(1) *Usual vs. Unusual* — But to say that "usual" treatments are morally obligatory while "unusual" ones are not, would be to let the status quo be the norm of morality. "It should be possible to say that even though something is not now being done, it ought to be. Adequate primary health care for urban ghettos and rural areas is unusual. That it is morally expendable because it is unusual seems preposterous. In the same light it does not seem reasonable to require a treatment simply because it is usually provided. If that were the case no change in policy could ever take place."¹⁵⁵

(2) *Useful vs. Useless* — According to Gerald Kelly, this use of the "means" approach defines "ordinary" means as "all medicines, treatments and operations, which offer a reasonable hope of benefit for the patient and which can be obtained and used without excessive expense, pain or other inconvenience."¹⁵⁶ But while the usefulness may be a major consideration in determining what is morally obligatory it does not follow that all "useful" treatment is obligatory, or that all "useless" treatment is elective. "There are, in the first place, grounds other than uselessness for which it would be morally acceptable to omit or cease to use a

medical means — repugnance of the procedure itself, cost, abhorrence of the social consequences such as separation from one's family, and the like. On the other hand, certain procedures might be useless to save or even to prolong the life of a patient, but could nevertheless be imperative for the patient's comfort."¹⁵⁷

(3) *Reasonable vs. unreasonable treatment* — Veatch therefore concludes that ordinary and extraordinary in this context "should be banned from further use", and that it would be clearer simply to speak of morally imperative and elective treatment. But we still have the problem of distinguishing between them. At this point Veatch makes what I feel is his most helpful and original contribution. Not that all the ingredients of his proposal are novel, but he has managed to draw together in a clear and convincing formulation a number of elements usually left somewhat scattered and unrelated in most treatments of the subject. It is an approach which also further expands and dovetails with much of what has been argued to this point.

2. The "Reasonable Person" Standard

There are several elements to this proposal for distinguishing between morally imperative and morally elective treatment. The foundation of this "entirely new perspective" is the patient's *right to refuse treatment*. The morality of these refusals is determined or articulated by means of two complementary criteria, that is, the *patient's perspective* and the *language of reasonableness*. They are both to be applied (but differently) to two classes of patient — the competent and the incompetent. Unpacking this approach is no easy task, but well worth the effort.

First of all the *competent* patient. Here Veatch, in my view, is not as clear or as thorough as one might like. There is a degree of ambiguity in the way he applies his twin criteria — patient's perspective and language of reasonableness — and there are some unanswered questions. He begins applying the twin criteria by claiming that, "From the patient centered perspective it should be sufficient for competent patients to refuse treatment for themselves whenever they can offer *reasons valid to themselves* — that is, out of concern about physical or mental burdens or other objections..." [emphasis added] (p. 110). Presumably this is an absolutely *subjective* test, and not a test which requires confirmation or justification by any other standard or objective criteria.

What confuses the issue slightly is the reference to "offering reasons". At first sight that could suggest the need to convince someone else (a physician? a court?) of one's "reasonableness" according to some objective norm or someone else's standards. It might seem to rule out as "valid reasons" what someone else or some other standard might classify as merely foolish or capricious whims, even though the decision to refuse treatment and to choose to die would presumably appear completely reasonable to the patient concerned. This ambiguity is not lessened by the further statement that, "... a refusal will be morally acceptable if it is *reasoned*, in the case of competent patients. . ." [emphasis added] (p. 112).

Yet in context Veatch appears after all to be proposing a completely subjective criterion or test for competent patients, that is, those able to decide for themselves. And in this I fully agree. For elsewhere he notes that for the competent patient the "moral requirements" are, "... what the patients would find reasonable. . ." (p. 113). And he observes (with approval) that, "... the right to refuse medical treatment, for any reason, is well established in the Western legal tradition. No competent patients (excluding prisoners) have ever been ordered to undergo any medical treatment for their own good by United States courts even if such a refusal would almost assuredly lead to death." (p. 104) And again (with apparent approval) he writes that, "There seems to be a clear consensus [in decisions of the courts] that the competent adult has the right to refuse treatments on apparently foolish or misguided grounds, even when the treatments may be as common and clearly life saving as a blood transfusion." (p. 121).

In effect then, for competent patients the "bottom line" is that there are no really "imperative" treatments viewed from the perspective of the right to refuse treatment. Refusal is always their right before the treatment begins or at any time during it.

I agree fully with the subjective criterion for the competent patient, yet note in passing that there remain some unanswered questions. Admittedly, on the basis of liberty as a basic human value, the competent patient should be able to refuse treatment on any grounds he wishes. That clearly and unequivocally establishes a "hands off" policy as regards *anyone else* interfering with that right and imposing treatment for any reason whatever. But what help can we be to the *patient* if and when he seeks advice as to good moral reasons or grounds for actually refusing treatment or choosing to die?

Veatch does indicate some such grounds when he refers to "physical or mental burdens"; and he does apparently hope that in his personal, subjective (and inviolable) decision-making the competent patient will apply the same "reasonable person" tests to potential treatments as *must* be done by patients' agents for incompetent patients (see below). But at the level of fundamental principles and values, the basic value of liberty may need here to be supplemented (though never displaced) by others if the advice given to such patients is to be balanced and helpful. One such supplemental value would be the patient's (social) obligations and responsibilities. He should consider for instance the implications for others (children, husband, wife, parents, etc.) of refusal of treatment and choosing to die. What are his responsibilities to them? Would their burdens be lessened or increased? These may not in the circumstances be primary considerations, but they do have a place in a patient's moral calculus.

We turn now to the *incompetent* patient, (i.e. one unable to express wishes) for instance the child, the senile, the comatose, the mentally retarded. As Veatch notes, for these patients we must look elsewhere than "reasons valid to themselves".

Assuming that for the "previously competent" at least, no clear wishes on the subject were expressed (while coherent) or are available, we must now turn for treatment evaluations of incompetent patients to the *reasonable man* standard.¹⁵⁸ Here what Veatch is proposing is clearly an *objective*, not a *subjective* criterion or test, and one of necessity made for the patient (by parents, guardians, other patient's agents or courts), not by the patient. But it too is intended to be patient-centered. (For a brief comparison of the "reasonable man" standard and "substituted judgment" and the relevance of each to such cases, see below, Ch. 8 — "Courts and Incompetent Patients".)

Justification for the application of this standard to the subject of refusing treatment can be found in its increasing use in the context of *informed consent cases*, where the same kind of question is raised. In those cases there appears to be a growing recognition that the "reasonable man" and not just the physician is able to judge whether certain medical information is significant enough that a patient would want to be informed of it.

In one such U.S. case for instance the judge concluded that, "whether or not Dr. Brown violated his fiduciary duty in withholding information is a question of fact to be judged by reasonable man

standards.”¹⁵⁹ In a recent Canadian case a Court of Appeal ordered a new trial for a doctor against whom a patient had won \$225,000 in a malpractice suit. The Court of Appeal judges decided that, “. . . The case should have been decided on *what a reasonably prudent patient* in the same situation given the same information would have done [emphasis added].”¹⁶⁰

Applying this “reasonable person” standard to our question one could argue that, “It is the same kind of question, whether it is reasonable to refuse a medical treatment once there is a particular established diagnosis and prognosis. Answering it does not require the help of medical training at all. While it is important to have medical training to determine the diagnosis, prognosis and alternative courses of treatment, deciding whether a particular treatment ought to be given (or accepted) is a normative question to be decided on the basis of ethical and other values. It is those value choices that the reasonable person can make without scientific or medical training.”¹⁶¹

As to what, more specifically the reasonable person considers a reasonable or unreasonable refusal, “A reasonable person would find a refusal unreasonable (and thus treatment morally required) if the treatment is useful in *treating a patient's condition* (though not necessarily life saving) and at the same time does not give rise to any significant *patient-centered objections* based on physical or mental burden; familial; social or economic concern; or religious belief [emphasis added].”¹⁶²

In my view this statement and test should be applied differently to the incompetent and the competent patient. For incompetent patients (to whom it is primarily and directly applicable) it comprises an objective and limiting standard which *must* be used in evaluating and making treatment decisions. For them this formulation is intended (or should be) to establish the outside limits of their right to refuse treatment as protected and claimed for them by others. But for the competent patient, whose right to refuse treatment is not limited by an objective “reasonable person” standard, the statement comprises good moral reasons and norms but does not as it stands leave room for the many other potential grounds for considering a treatment merely elective, grounds which may appear to that patient completely reasonable, though perhaps not to others.

The above citation is not really far from the definitions of “ordinary” proposed by Pope Pius XII, Kelly and others; but this formulation provides needed criteria and a standard to resolve

particular cases, and avoids the ambiguities of the term "ordinary". In particular it eliminates two latent ambiguities, both having to do with the "patient's perspective".

The first potential ambiguity is found in the Pope's statement that "extraordinary" treatment is not required. One might conclude from that paragraph at least, that physicians could morally stop a treatment they found 'extraordinary' (that is unreasonable), even though the patients or their agents did find it reasonable. The patient centered perspective in the above statement is unequivocal in that respect.

Secondly, the papal statement may also have taken the focus off the patient's perspective by saying that treatments are extraordinary if they impose a grave burden on oneself or *another*. It should be acknowledged that concern for others is a legitimate basis for refusal of treatment by a *competent* patient. But this patient centered formulation ought to lessen the danger that a physician or a patient's agent will use "burden on others" as a reason to judge treatment unreasonable for an *incompetent* patient.

One can never be too careful in making that point clear and unambiguous. It should be noted that not everyone is equally convinced on that score. Richard McCormick for instance wonders why, if burden on others is a legitimate justification for making treatment of a *competent* patient unreasonable, it cannot also be so for the incompetent patient.¹⁶³

It seems difficult enough to arrive at an objective judgment for another and in the interests of that other without bringing in considerations of burdens and benefit to others than the patient. Even without those considerations there will be such disagreement and uncertainty, that sometimes the judgment of the reasonable person will have to be determined in the courts. We have already argued that clear lines should be drawn and maintained between the condition and interests of the patient on the one hand, and those of others on the other hand. The same arguments apply here on this point. To think otherwise is to increase the risk of promoting the interests of others, including those of the physician or patient's agent, to the detriment of those of the patient.

How then do all these considerations specifically relate to our quality of life issue? In fact all these points — the patient centered perspective, the standard of reasonableness, treatment useful in treating a patient's condition — make more concrete and specific

what was already noted and argued concerning quality of life. But at the same time these points in turn require the addition of those clarifications and distinctions made earlier.

For instance the notion of the "reasonable person" provides us with a useful but formal standard for making judgments to treat or refuse treatment based on the patient's condition or quality of life. But the substantive determination of what in fact is "treatment useful in treating a patient's condition", often cannot be practically and helpfully made without applying the distinction between human biological life and human personal life.

In other words, treatment could be "useful" for many purposes, but in our view the crucial (and reasonable) question is what level, condition or quality of life it will maintain. If for instance it will only maintain *biological* life, but not at least a minimal degree of *personal* life (and an absence of excruciating and intractable pain) then according to what we have already argued above, it will not be "useful" treatment.

We find confirmation for the "reasonable person" standard in a well known and recent court case, the Karen Quinlan case.

In the Quinlan case, the New Jersey Supreme Court argued that: (1) Karen Quinlan had a right to self-determination (the Court said 'privacy') where treatment is concerned; (2) that she is in a noncompetent and vegetative state leaving her incapable of exercising her right to withdraw treatment; (3) that it may be exercised on her behalf by her family and guardian. Then most interestingly it stated: 'If their (family) conclusion is in the affirmative, their decision should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them.' This is an appeal to what most of us, in similar circumstances, would do — as reasonable people with healthy outlooks on the meaning of life and death.¹⁶⁴

But can we be still more specific, more concrete about applying the "reasonable person test" and the "useful treatment criterion" to withdrawal of treatment judgments? Specifically, *what treatment* may be withdrawn? If care and comfort must continue to be provided to the dying or seriously damaged patient, then is it possible in practice to distinguish between *care* which becomes imperative and *treatment* which becomes elective? What in effect is the difference between care and treatment in this context? This is a huge question, and many practical difficulties remain to be tackled.

However, building on points already made, it is possible to be still more specific. By way of illustration, consider again the Karen

Quinlan case.¹⁶⁵ The attending doctors diagnosed her as being in a "persistent vegetative state", and the prognosis was that she would not regain a "cognitive and sapient state". According to the "useful treatment", "reasonable person" criteria as discussed, further treatment was not indicated. That was her father's conclusion, and he accordingly requested that (only) her *respirator* be turned off. As observed above, the New Jersey Supreme Court decided he could exercise the right to withdraw treatment on her behalf and he did. Once the respirator was switched off she began to breathe spontaneously, though she remained in a "vegetative state" (i.e. a state of cerebral death).

Could her father have requested, before or after she breathed spontaneously, that not only her respirator be turned off, but also that she no longer be *fed intravenously*? Though he himself clearly classified the respirator as useless (or "extraordinary") treatment, and the intravenous feeding as useful ("ordinary") treatment (or care), it would be morally justifiable (if not preferable) to consider both the *respirator* and the *intravenous feeding* as equally "useless" treatment. Assuming, as the medical diagnosis allows, that she does not feel hunger, then such feeding is only another "useless" treatment. It does not treat her condition. It only prolongs dying by providing nourishment.

If intravenous feeding contributed to her care and comfort, then of course it should be continued, as care and comfort remain imperative no matter what. But there are apparently alternative procedures less likely to prolong dying yet able to offset any possible discomfort in that regard. "To be on the safe side, perhaps we should say that she might experience dehydration. That is now the purpose of a glucose drip: to give the comfort of a cup of cool water to a patient who has entered upon her own particular dying. If a glucose drip prolongs a patient's dying, it is not given for that purpose, or as means in a continuing useless effort to save her life. . . . there are certain sugars which it might be possible to use in cases such as this to give water for hydration without metabolizing calories and prolonging the dying process."¹⁶⁶

3. Language or Substance

Finally, it is worth noting that some of those who argue that the "ordinary/extraordinary means" approach should be retained as a defence against quality of life considerations, seem more concerned

with concerns of language than of substance. One example is the position of Leonard Weber, referred to above.

A close look at his view suggests that in the final analysis, behind his ordinary/extraordinary language, lies a judgment to initiate, continue or discontinue treatment because of a quality of life factor such as the patient's *damaged* condition, the *excessive burden* imposed by further treatment, or *severe and permanent handicaps* resulting from treatment. He writes for instance, "One can even talk about treatment imposing an excessive burden when it is the timing of treatment that results in a *burdensome* life. If for example, the oxygen supply to the brain has been stopped and the opportunity to resuscitate such a person only comes when it is probable that *extensive damage* has already been done to the brain, it should be considered an extraordinary means to attempt to restore normal blood circulation, no matter how common the procedure. By saving the life of the patient at this time, an *excessive burden* would be imposed. . . The second guideline, then is this: treatment imposes an excessive burden on the child himself if it involves a long, drawn-out battle against death or if the treatment itself results in a *severe and permanent handicap*. Such treatment should be considered extraordinary and may be withheld without violating the child's right to life [emphasis added]." ¹⁶⁷

In so far as Weber's basis for decision-making is the patient's *damaged condition* it is difficult, if not impossible, to conclude that finally and substantially he is making judgments based on quality of life, no matter what his language. And to camouflage this reality behind the "ordinary/extraordinary" language appears to serve no useful purpose whatsoever. It could even be dangerous because, "What is important in these matters is that the line be drawn in the proper place. Language itself does not draw such lines. . . not attending to it could easily lead to allowing that line to slip around in a way that is ultimately unfair to the incompetent patient." ¹⁶⁸

B. Euthanasia or Allowing to Die with Care?

If, as has been argued, it is sometimes morally justifiable on the basis of quality of life considerations to discontinue or not initiate life support treatment, the next question is, how far can one morally go? Specifically, is not only *allowing to die* morally acceptable, but

sometimes *killing* as well? Is there really any significant moral difference between them, once the decision has been made not to treat or to discontinue treatment? All the arguments I have made to this point are intended to support only allowing to die (and that only under certain specified circumstances), but not killing or intending death.

But there are of course competing positions and many moral arguments advanced in their defence. Lest I seem to be claiming or allowing wider moral parameters and conclusions than intended by justifying quality of life decision making, I must now attend to and attempt to refute some of those arguments. In doing so I hope to bring still more clarity and precision to the meaning, application and limits of quality of life judgments.

One could say there are in effect two related positions opposing mine. Or perhaps more accurately there are two interlocking stages or levels in the opposing view. On one level it is argued that there really is no morally significant difference between allowing to die and killing. The next level [often, but not always dependent on the first] is the view that (therefore) killing is (sometimes) morally justified. These levels or elements could be combined in the form of a syllogism, the assumed major of which is that allowing to die is (sometimes) legitimate. Adding the "euthanasia" terminology often used in these expositions (a usage which I shall maintain is mostly confusing and erroneous), the syllogism would be this:

(Major premise):

Allowing to die [passive or indirect euthanasia] is sometimes morally legitimate.

(Minor premise):

Allowing to die [passive or indirect euthanasia] and *killing* [active or direct euthanasia] are morally equivalent.

(Conclusion):

(Therefore) *Killing* [active or direct euthanasia] is sometimes morally legitimate.

I have no quarrel with the major premise. Much of the foregoing was obviously an attempt to establish just that point. My quarrel is with the minor premise and the conclusion. It would not, of course, be entirely accurate to suggest by using the above syllogism, that anyone who holds one of its elements, necessarily and explicitly holds the others. Clearly some hold that killing is sometimes morally legitimate, without holding (at least explicitly) that allowing to die

and killing are morally equivalent. And some who hold that allowing to die and killing are morally equivalent, use a different major premise and conclude that neither allowing to die nor killing are morally legitimate.

Still other variations exist as well. And in some expositions only one of the elements of the syllogism is professed, independently of the other two. The purpose here in using that syllogism is partly to identify the major threads of the issue in order to deal with them separately, and partly to note how those threads are typically, though not always, woven together.

Let us consider first of all the above "minor premise" that allowing to die (so-called "passive" or "indirect" euthanasia) and killing (so called "active" or "direct" euthanasia) are morally equivalent. There are in reality two related points affirmed in that view, both of which merit separate consideration.

The first concerns the appropriateness of using the term "euthanasia" at all; the second is the more substantive issue as to whether "allowing to die" really is morally equivalent to "killing". The two points are closely related in that partly *because* (it is argued or assumed) "euthanasia" is the denominator common to both allowing to die ("passive or indirect euthanasia") and killing ("active or direct euthanasia"), *therefore* allowing to die and killing are morally equivalent.

1. The Problem of Language — Euthanasia as "Killing", not "Allowing to die"

But is the term "euthanasia" really appropriate to both? I think not. As anyone who has followed the literature and the debates in recent years is aware, the term "euthanasia" is used to mean so many very different things that its use confuses and question begs more than it clarifies and answers. A few continue to mean what the greek word literally meant — "a good death", and intend by that what others would now more generally (and helpfully) label, "allowing to die with care,"¹⁶⁹ a form of care which excludes killing. But the more common and probably fixed meaning in our times is that of *directly killing* the dying patient.

To use the same word in these two different senses only covers up and blurs the essential distinctions between the two approaches.

That fact "justifies a moratorium on its use. . . Formulation of any public policy dealing with these issues will consciously or unconsciously have to make these distinctions or have a confusing policy. For thorough ethical analysis, it is vital to have those distinctions spelled out."¹⁷⁰

Nor do all the various qualifiers often attached to "euthanasia", really escape that confusion or make the distinction between its usages sharply enough. "We speak of 'active' or 'passive' euthanasia, of 'directly' or 'indirectly' disposing a patient to death, of whether death came by acts of omission or by acts of commission, by action or by refraining. I would get rid of all of these terms. We are misled to them by our popular and irreformable usage of the word 'euthanasia' — for choosing death as an end. Since we cannot restore the word to its original meaning, I think we simply must speak of the immorality of euthanasia and of the morality of 'dying well' — or, more soberly of 'dying well enough'."¹⁷¹

It is worth noting that the inappropriate and confusing usage of the term "euthanasia" in our times is sensed not only by ethical analyses, but by some legal analyses as well. David Louisell for instance writes, "The word 'euthanasia' does not include the withholding of extraordinary means to preserve life. To call the mere withholding of extraordinary means 'indirect voluntary euthanasia' is, taking into account the currently accepted meaning of 'euthanasia' as deliberate killing, a confusing of terms that cannot conduce to precision of thought."¹⁷²

The moralist Joseph Fletcher in his many writings, is one of those who uses the word euthanasia for both allowing to die with care, and for direct killing.¹⁷³ For the former he adds the qualifier "indirect" euthanasia, and for the latter, "direct" euthanasia (others use the terms "passive" and "active" to distinguish them). He claims to be basing this usage of "indirect" euthanasia on the use of the term "indirect voluntary" in Christian ethics. He argues that because death occurs by omission, rather than directly by commission, and is not induced but only permitted, it is appropriately called "indirect voluntary".

But Fletcher misunderstands the term "direct" and "indirect" as they are used in ethics. In fact the expression "indirect voluntary" is normally only used when two effects are caused by the same action, and in this context that is not really what takes place with most decisions to stop or withhold life-sustaining treatment.

Paul Ramsey in my view compellingly refutes Fletcher on this and related points:

The difference between only caring for the dying [*i.e.* allowing to die with care], and acts of euthanasia is not a choice between indirectly and directly willing and doing something. It is rather the important choice between doing something and doing nothing, or (better said), ceasing to do something that was begun *i.e.* life sustaining treatment, in order to do something that is better [only caring for the dying] because now more fitting. In omission no human agent causes the patient's death, directly or indirectly. He *dies his own death from causes that it is no longer merciful or reasonable to fight* by means of possible medical interventions. . . In any case, doing something, and omitting something in order to do something else, are different sorts of acts. To do or not to do something may, then, be subject to different moral evaluations.¹⁷⁴ [emphasis added]

The only medical act in caring for the dying which might theoretically be called "indirect euthanasia" is the use of pain killing drugs which may also reduce a patient's strength and hasten death. The use of such drugs is justified on the grounds that relief of pain is the "directly voluntary" action, whereas the fact that death may be hastened is only "indirectly voluntary". Here we do have two effects of the same action.

But a number of observations should be made at this point. First of all there is a difference in this regard between the giving of pain killing drugs and the withdrawing or withholding of life-sustaining treatment. In the second case, as Ramsey rightly insists, there is no double effect, and therefore no "indirect" euthanasia. That being the case, this one instance hardly justifies the use of the term "indirect euthanasia", for withholding or withdrawing treatment in general.

Secondly, there is serious question in many cases as to whether pain killing drugs really do hasten death more quickly than extreme pain itself would do, left unaided by drugs. Extreme pain is also weakening and life-shortening. Because of this, "the relief of pain itself may well lengthen life: it will certainly enhance it."¹⁷⁵

Thirdly, at least some of those in the health care professions who work constantly with pain killing drugs for the dying do not in fact think of this action as any form of euthanasia, but rather as what it directly and clearly is — care for the dying. Cicely Saunders for instance, writes, "If you relieve a patient's pain and if you can make him feel like a wanted person — which he is, then you are not going to be asked about euthanasia. . . euthanasia is an admission of defeat, and a totally negative approach. One should be working to see that it is not needed."¹⁷⁶

And lastly, legal writers as well are not necessarily inclined to call even these actions of giving pain killing drugs, "euthanasia", or to see any dangers of legal liability in their use. As one such writer notes, "Thus a provision in the British Euthanasia Bill of 1969 works a disservice to clarity of analysis when it couples a provision authorizing true euthanasia, with one declaring that a patient suffering from an irremediable condition, reasonably thought in his case to be terminal, shall be entitled to the administration of whatever quantity of drugs may be required to keep him free from pain. There is no serious practical question of the present legality of such use of drugs nor any genuine problem with its ethicality."¹⁷⁷

What of the terms "active" and "passive", "positive" and "negative" euthanasia? As with the terms "direct" and "indirect" euthanasia, or the use of "omission" and "commission" applied to our issue, these as well are more confusing and inaccurate than helpful and for about the same reasons. Euthanasia itself in its customary usage is of course an "active" choice of death and the means to accomplish it, just as much as it is "direct" not "indirect", and a "commission" not an "omission". But that does not mean allowing death with care is, "... correctly characterized as 'passive' euthanasia (a passive choice of death as an end or by negative means). Death's cause is not advanced by acts of omission or by refraining. Death's cause is advanced by the disease state itself, which it is now useless to fight."¹⁷⁸

To conclude that there is, "nothing more to be done" to cure or save a life, does not mean a physician has nothing further to do but be "passive" or "negative" about the patient's well being. As already argued above, there are many active procedures to be considered at this point in the form of appropriate *caring* treatment now that *cure* is no longer possible; and none of them need, or should, involve choosing death or the means to death, any more than did the no longer useful *curative* treatment. "It is entirely misleading to call reasonable decisions to cease curative treatment negative euthanasia; they are part of good medical treatment, and always have been."¹⁷⁹

2. "Allowing to Die" and "Killing" not Morally Equivalent

Now that we have dealt briefly with the terminological problem, let us address still more directly the substantive issue as to whether

"allowing to die" really is morally equivalent to "killing", the second of the two related considerations in our syllogism's minor premise. Whatever the terminology used, the more significant issue is of course whether or not there is a moral difference between the realities of killing and allowing to die.

Clearly not everyone agrees with the contention that there *is* a significant moral difference between them. The most recent and most influential statement of the opposite view is that of the philosopher James Rachels.¹⁸⁰ He argues that the distinction is always morally irrelevant. Rachels takes issue with the position of the American Medical Association of 1973 which on the one hand opposes "the intentional termination of the life of one human being by another", but on the other hand condones the cessation of treatment in a carefully delineated range of cases, namely when, (1) patients are being sustained by "extraordinary" means, (2) there is irrefutable evidence of imminent biological death, (3) the patient or the family is able to give consent.

To establish his view that the distinction between those two options, killing and letting die, is without moral importance, Rachels suggests two cases between which he claims there is no moral difference even though one involves killing and the other letting die. Here are his cases:

In the first, Smith stands to gain a large inheritance if anything should happen to his six-year-old cousin. One evening while the child is taking his bath, Smith sneaks into the bathroom and drowns the child, and then arranges things so that it will look like an accident.

In the second, Jones also stands to gain if anything should happen to his six-year-old cousin. Like Smith, Jones sneaks in planning to drown the child in his bath. However, just as he enters the bathroom Jones sees the child slip and hit his head and fall face down in the water. Jones is delighted; he stands by, ready to push the child's head back under if it is necessary, but it is not necessary. With only a little thrashing about, the child drowns all by himself, "accidentally," as Jones watches and does nothing.

Now Smith killed the child, whereas Jones "merely" let the child die. That is the only difference between them.¹⁸¹

But as a number of other commentators have argued, the view professed by Rachels is not entirely convincing for several reasons. Most agree that the traditional case for a moral difference remains more persuasive.¹⁸² We will consider first the more negative reasons which argue against Rachels, then the more positive moral reasons arguing for affirming and maintaining the distinction between them, and for maintaining the prohibition against euthanasia, or killing.

First of all, it is easy to agree with Rachels that in the two cases he proposes the bare difference between killing and letting die in itself does not make a moral difference. But that does not mean the distinction is always morally irrelevant — only in the cases similar to the ones he proposes.

There are important dissimilarities between his cases and those envisioned by the American Medical Association statement. For one thing Rachels' cases involve two *unjustified* actions, whereas one set of the A.M.A. cases involves unjustified killing but the other involves justified allowing to die. For another, in Rachels' cases both moral agents are morally reprehensible and blameworthy. Jones after all had at least a duty of beneficence requiring him to rescue his cousin under the circumstances.

This latter point is what makes the distinction between the cases of no moral significance, *not* the point Rachels considers decisive, namely that there is no moral difference between killing and letting die in themselves. Were it not for that equal moral responsibility in Rachels' cases we might readily have found a relevant moral distinction. For instance, "... suppose the motives of the actors were benevolent or neutral rather than malevolent. It is possible to assume that many or most medical practitioners have benevolent or at least neutral motives when they make decisions about their patients. In such cases the distinction between killing and allowing to die may not be morally irrelevant."¹⁸³

That last point and possibility is directly relevant to the cases envisioned in the A.M.A. statement, in that in them (unlike Rachels' cases) an agent is said to be responsible for taking life, but not always obliged to preserve it. While a physician may have a duty to provide a life supporting treatment if the patient requests it, he has no duty to provide it and may *not* provide it if the patient does not ask for it or consent to it. After all, it is only the patient's request and consent which turns what otherwise would be assault, into a legitimate treatment.

Another way of making the same point against Rachels is to note that he (like others), "... too easily concludes that *motives* alone determine the morality of killing or allowing to die. Thus he too quickly dismisses as irrelevant the *methods* of bringing about death [emphasis added]."¹⁸⁴ This observation is equally applicable to Fletcher's thesis, in that he too argues in almost all his writings on the subject that the intention or end in view (in killing and allowing to die) is the same, and that, "As Kant pointed out, if we will the end we will the means."¹⁸⁵

Quite true, the end in view might be the same. But that does not say all that is to be said. We can, after all, properly and legitimately desire death yet recognize that there are *different means* available to that end, some of which may be justifiable, and some not. It remains true that, "... where there are more than one means to this same end, to will that end leaves open the choice among means. A means may be right, another wrong, to the same end."¹⁸⁶

3. On Maintaining the Distinction

Time now to indicate some other moral reasons for maintaining the distinction, reasons which in my view remain valid in terms of policy formulation *even if* one did not agree that there is an intrinsic moral difference between killing and letting die. In my view these reasons also refute, or at least shed serious doubt upon, the assertion that killing (euthanasia) is sometimes morally legitimate.

Some reasons have already been suggested earlier in the context of other aspects of our issue. But it might be helpful at this point to draw them together more explicitly now for this purpose, adding some not yet referred to. There are many such arguments, but three in particular merit our attention here. The first is an argument from medical fallibility; the second is a form of "wedge" argument; the third is an argument from medical care and trust.

The argument from *medical fallibility* is based on the empirical possibility and fact that so called "irrefutable" medical prognoses of imminent death can be and have been wrong. To kill is to preclude any chance for life in the event of such error or eventuality; but to stop life sustaining treatment may not deny the patient that chance. This appears to have been the thinking of Mr. Quinlan, the father of Karen Quinlan.

In requesting that his daughter be removed from the respirator but not killed he wished to leave open the possibility that the doctors might be wrong in their diagnosis and prognosis that she was in a "persistent vegetative state" with no hope of returning to a "cognitive and sapient state". "There may of course, be utterly no empirical possibility of recovery in some cases since recovery would violate a law of nature. However, judgments of empirical impossibility in medicine are notoriously problematic. . . And in all the hard cases I think we do not know that recovery is empirically impossible, even if good evidence is available."¹⁸⁷

The *wedge argument* considers the likely *consequences* for individual and society of any move in the direction of allowing killing in our cases. One kind of wedge argument maintains that if society ever accepted euthanasia it would be the "thin edge of the wedge", sooner or later putting all life in a precarious position.

Possibly tolerating active killing for mercy will lead to increase in other active killings, not because of any logical connection, but simply because those who are not careful may mistake one form of killing for another, or those who want to actively kill to benefit others will rationalize their actions by claiming that they are committed as acts of kindness to the recipient.¹⁸⁸

There is little doubt that some form of carefully controlled euthanasia-killing would eliminate a certain amount of suffering in some cases, but would that obvious benefit be worth the risks in terms of wider and long-range consequences? "In a perfect society, or even one where trust between citizens and state, doctors and patients, aged and young, could be taken for granted, such fears need not arise. And even in our own society, the risks may not be overwhelming. But so long as the risk is there at all, it must be weighed against the benefits which lawful euthanasia could bring to those who want to be relieved from great distress. Should we run the risk of severe inroads on the rights of future patients in order to help present sufferers? I believe that caution speaks against such a gamble."¹⁸⁹

In other words there is a crucial consideration to be weighed here even, or perhaps especially, by those who do not subscribe to an absolute prohibition against killing on religious or other grounds, or to an intrinsic moral difference between killing and letting die. They still have to confront the question from another perspective — that of *maximizing social utility*. The specific and remaining question facing proponents of euthanasia who do not acknowledge an absolute prohibition against killing is this: would such a change in our moral rules — towards a form of euthanasia-killing, have a higher social utility than our present moral rule which prohibits it?

Combining the wedge argument with rule-utilitarianism (*i.e.* society ought to adopt the rule with the better consequences for the common good), one commentator observes that, "If wedge arguments raise any serious questions at all, as I think they do, they rest

in this area of whether a code would be weakened or strengthened by the addition of active euthanasia principles."¹⁹⁰

He goes on to situate rules against killing in the wider context of our moral code, noting that, "Rules against killing in a moral code are not *isolated* moral principles; they are pieces of a web of rules against killing which forms a moral code. And if, as I believe, moral principles against active killing have the deep and continuously civilizing effect of promoting respect for life. . . then this seems an important reason for the maintenance of the active/passive distinction [in our terminology the killing/letting die distinction]."

There is yet a third argument for maintaining the distinction between killing and letting die and the prohibition against killing or euthanasia. It has to do with the inextricable relationship of this distinction to *medical care*; insofar as patients are secure in the knowledge that physicians will not kill them (but also will not needlessly prolong dying), the distinction and the prohibition comprise a large part of the basis of patient trust in physicians.

It is true as noted above, that killing some patients might well provide relief for those patients from unbearable pain and suffering; it is equally true therefore that the somewhat ambiguous medical principle, "first of all do no harm," does not in itself necessarily rule out the direct hastening of death — for a particular suffering patient, that *could* be a benefit and therefore an avoiding of harm.

But if we extend "harm" as a norm more widely than to some individual patient and apply it to the patient-physician relationship in general, one suspects that to allow killing would seriously compromise the expectation of moral limits and boundaries on which patient trust is based. In the absence of compelling arguments to the contrary, one is intuitively inclined to agree that, "Euthanasia would threaten the patient-physician relationship: confidence might give way to suspicion . . ." ¹⁹¹

In view of the radical change in policy involved in any shift towards euthanasia, even voluntary euthanasia, the burden of proof surely is on the proponents, not the opponents of the change.¹⁹² After all, voluntary euthanasia is radically different from refusing treatment, allowing a patient to die, or securing the right to die. What proponents of voluntary euthanasia want is much more than any of those, and more than suicide as well. What is being asked for seems closer to a "right to be dead" than a right to die, in that the

patient should be allowed to be dead *when he wishes to*, and the *physician* is to be the agent of that death. Such an agency would radically transform the physician's present role and ethics, and in my view to the detriment of both. In the absence of arguments which convincingly dispel fears for the continued health of patient trust in physicians in the eventuality of such a policy shift, we seem bound to conclude that the present policy in this regard has not been proven essentially wanting, that a shift is not necessary and would not be generally beneficial to patients.

This conclusion holds even in the face of cases of excruciating and intractable pain and suffering. As argued earlier in the paper this is a "quality of life" consideration which may in some instances justify allowing to die (with care). But not killing. In the first place, from the empirical point of view, there is convincing proof available that the art of pain control is now so well advanced that such cases are increasingly rare.¹⁹³ And in the second place, "... it is not clear that we should build a social ethic, a professional ethic, on the 'Grenzfall', the boundary case. An emergency ethic is just that, and should not be taken to provide the ethos for normal medical practice. Hard cases make bad social and professional ethics as well as bad law."¹⁹⁴

4. Some Possible Exceptions?

Only one question remains to be answered — granting the general prohibition against killing, are there any morally defensible exceptions at all? In other words are there any cases in which one may not only *allow to die* but also cease care and directly *cause* death? There may be two such cases or conditions according to Paul Ramsey.¹⁹⁵ Causing death in both cases becomes morally justifiable (he argues) only because the patient becomes "inaccessible to human care".

The first kind of case involves "the permanently and deeply unconscious person," and the justifying principle he proposes is, "Never hasten the dying process except when it is *entirely indifferent to the patient* whether his dying is accomplished by an intravenous bubble of air or by the withdrawal of useless ordinary natural remedies such as nourishment."¹⁹⁶ For the sake of argument we should of course assume that such a patient is "defineably"

alive, even though Ramsey's patient as described may already be dead as a person according to the standards proposed earlier.

The justifying reason is not one of mercy for the patient — that remains an insufficient reason either for allowing to die or directly hastening death. The point is that the patient in this case is beyond reach, not able to sense the presence of others, not suffering, and would not feel hunger if no longer provided nourishment. Such patients are beyond relief; only the suffering of relatives might be relieved by taking such an action. Ramsey is not arguing that it is always an easy matter to determine whether in fact a patient is completely beyond awareness of others, but wonders whether in the cases where this can be determined there might not be a "useless extension of care".

The second kind of exceptional case he proposes is the "kind of prolonged dying in which it is medically impossible to keep severe pain at bay." As I have already considered this case and generally rejected it, I need not comment on it again here.

But what of the first kind of case? Is Ramsey's argument convincing? At first sight perhaps. After all, if the patient really is "entirely indifferent" to how his death is accomplished, why not hasten his death, especially if doing so might relieve the suffering of relatives and others. Certainly such a prognosis (permanent and deep coma) justifies allowing to die, that is the cessation of life sustaining treatment, including (as in a Quinlan type case) stopping of both the respirator and intravenous feeding. That is in fact the position I argued earlier. But Ramsey does not here convince me to go further by allowing such a patient to be killed.

One may concede many points to Ramsey and others, but yet stop short of agreeing such a patient may be killed. Such a patient is probably "entirely indifferent" to how death is accomplished, is possibly no longer a person in the strict sense by the "definition" proposed earlier in the paper, is no longer responsive to our presence or care, and is probably not suffering. But may we still not have a duty to provide "appropriate care", even if that might now be reduced to only a glucose drip to avoid the possible experience of dehydration?

As some other commentators have noted about this position of Ramsey's, to base this view on whether or not something is a matter of indifference to the patient might be more or less equivalent to

legitimizing a conscious patient's wishes to be killed. After all, in both cases the decision to kill or not is made to hinge on the *patient's attitude* — either his desire (if conscious) or presumed indifference (if unconscious). And as noted above, a patient's wish to be killed or his right to die is one thing, but that the physician should be the agent of that death is quite another. It is against precisely such a shift in policy, towards empowering physicians to be such agents, that I have been arguing.

We are therefore inclined to agree with the view that Ramsey's position on this matter, "... either contains the seeds of a justification of hastening death by request or must be overridden by considerations extending beyond patient preference."¹⁹⁷

C. Conclusions: Refusing Treatment and Causing Death

(1) The "ordinary/extraordinary means" criteria are extremely vague, relative and inconsistently used in literature and practice. The distinction between "ordinary" and "extraordinary" treatment sometimes means "usual vs. unusual", and sometimes "useful vs. useless".

(2) In the final analysis (and whether acknowledged or not), the "ordinary/extraordinary means" criteria and vocabulary cannot avoid consideration of quality of life factors. It is quite inaccurate to argue as do some in defence of the "means" tradition that it focuses on factors quite other than quality of life ones.

(3) The "ordinary/extraordinary means" terminology should be discarded, and in its place one could more helpfully speak of *morally imperative vs. morally elective* treatment, a distinction based upon the *patient's right to refuse treatment*. Whether a treatment is imperative or elective in a given case is determined by the use of two complementary criteria, namely the *patient's perspective* and the *reasonableness* of the treatment.

(4) For *competent* patients, the test as to whether a treatment is patient centered and reasonable is a *subjective* test. That is,

competent patients have the right to refuse treatment for themselves (including life saving treatment) on any grounds acceptable to themselves. But ethically the competent patient in making his decision will weigh not only his *liberty* to request or refuse treatment, but also his social *obligations and responsibilities*.

(5) In making treatment decisions for incompetent and non-competent patients, the test should be an *objective* and not a subjective one. It should be a patient-centered "reasonable person" test. A reasonable person would find a treatment unreasonable if it is not useful in treating a patient's condition, and imposes a significant physical or mental burden on the patient.

(6) Both for substantive and semantic reasons, the terms "passive euthanasia" and "allowing to die" should not be used as if they were equivalent. The word "euthanasia" (no matter what qualifier is placed before it) generally connotes "killing", and not "allowing to die". And "killing" and "allowing to die" are not morally equivalent.

(7) To "allow to die" by withholding useless treatment is not a direct or indirect, active or passive cause of the patient's death. The patient in such a case dies his death from causes which it is no longer reasonable or beneficial to that patient to fight by medical means.

(8) Even though similarity of *motives* may suggest no moral difference between an act of killing and an act of allowing to die, motives are not the only morally relevant considerations. If two further ingredients are added, namely the *methods* used to bring about death, and the *duty* or lack of duty to provide treatment, then a moral distinction between killing and allowing to die can be maintained.

(9) Apart from strictly religious prohibitions against (active) euthanasia, there are several compelling non-religious arguments against its moral legitimacy. One is the argument from *medical fallibility*. Another is the *wedge* argument. Though killing a particular patient could possibly be beneficial to that patient, the consequent risk of gradually eroding society's respect for the sanctity of life may ultimately be more non-beneficial to more people than the continued suffering of this one patient. A third argument against

(active) euthanasia turns on the consequent danger of further eroding *patient/physician trust* if physicians were to be identified as agents of death.

. . . You see that's how it is. The infirm help the sick, the poor the needy. It is not the mighty who are going to find the solution but those who themselves are helpless. It isn't the strong who know the secret of healing, but the weak. An asocial child and a cretin join forces to help another cretin. That's the way it goes with our school, and that's how it's going to be the world over.

— Johannes Maria
Simmel

. . . legal language is pretty well adopted into common speech; the spirit of the law, born with schools and courts, spreads little by little beyond them; it infiltrates through society right down to the lowest ranks, till finally the whole people have contracted some of the ways and tastes of a magistrate.

— de Tocqueville

It is ironic that now that medicine has developed the capacity to be helpful in a variety of ways, it has lost much of its capacity to communicate compassion, so central to the healing process.

— David Mechanic

Chapter 6

Rights and Responsibility in Ethics, Law and Medicine

A. Utility of the Rights Model, the Law Model

Up to this point the concern has been largely to provide a moral analysis of some of the ingredients of "quality of life" decisions, but without very explicitly as yet dealing with the "who decides", "who controls" question. I have attempted to delineate a normative notion of person and of death, argued for the criteria of "useful treatment", the "reasonable man's judgment" and the "patient's perspective". I have defended the distinction between "killing" and "letting die" and the continued prohibition of euthanasia.

1. The "Who Decides", "Who Controls" Question

But there remains another dimension to consider more explicitly than we yet have and that is, who *controls*, who *decides* when to terminate treatment, or the timing and manner of death, or what relative weight and priority to give to certain "definitions", criteria and guidelines?

The medical and moral complexities and variables in actual cases rule out the mechanical application of precise definitions and guidelines. For example, thanks to advances in medical technology and our increased power to control death by making reversible (even though "artificially") functions previously irreversible, the material

elements which count as death are in a real sense subject to manipulation or at least "re-definition".

In the Quinlan type case for instance (a "persistent vegetative state"), faced as we are by a new type of existence somewhere between life and death, the central question is not just whether the patient is alive or dead, but though alive, whether we may cease treatment and who decides it.

For this and similar reasons the crucial ethical questions in our issues will increasingly be resolved not by the application of rigid definitions, but by on the one hand the formulation of clearly articulated yet sufficiently flexible *guidelines*, and on the other hand more attention to the "who controls", "who decides" type of question. Questions of this kind are usually understood as questions about *rights*, that is, who has the right to control and who does not have the right to control.

Therefore some attention will now be directed to the meaning and implication of "rights language" in our issues. There is little doubt that the rights approach is the most popular, most typical one adopted for the assignment and division of duties and obligations in problems of medical ethics. The typical questions asked in attempting to resolve the issues are for instance, "Who has a *right* to decide?", "Does one have a *right* to do such and such?", and our attention tends to be largely focused on issues such as the right to refuse treatment, the right to life, the right to die, the right to health care, and the like.

The concept of rights tends to be looked upon as the *link between morality and law*. Therefore an analysis of the pros and cons of the rights language, the rights model, in these medical questions is of direct relevance to a paper such as this one, directed as it is to a law reform project attempting to formulate policy sensitive both to moral values and the role of law.

The question is whether in medical ethics the "rights model" is the one most able to incorporate and account for the many relevant dimensions and dynamics involved in our medical issues; if not, is there a better alternative model or approach or a combination of approaches? The language of rights is of course central to the concerns of law (though not all of law), which largely determines what is lawful or unlawful on the basis of a determination of rights, and expresses these rights in the form of laws or rules. Therefore a question about the appropriateness of the model of rights for the resolution of these ethical issues is at the same time a question about the appropriateness and sufficiency of law itself in these same issues.

Several cautions and disclaimers are in order at this point. First of all, this section is not intended to be a thorough analysis of the rights question. It is only a very abbreviated and shorthand comparison of the pros and cons of two essential and complementary, but in some respects different approaches — the ethic of rights and the ethic of responsibility.

The high praises to be sung in this chapter for an ethic of responsibility are not meant to imply that we have here an “either-or” question, or that we advocate a rejection of the ethic of rights. This paper itself earlier stressed the centrality of rights such as the right to refuse treatment, and the paper’s concluding recommendations will indicate several areas in which clearer and stronger statements in law of some relevant rights and duties may be urgent and overdue. In fact I have few if any reservations about the *existence* and *possession* of rights in these issues — only some reservations about the appropriateness and sufficiency of *appeals to legal translations* of these rights in some circumstances.

The thesis advocated here is quite simply that in the (largely justified) concern with questions of rights in medical ethics, medical decision-making and related public policy, there may be a real danger of overlooking some urgent dimensions more accessible to an ethic of responsibility than to one of rights alone. The stress will be put on the former ethic largely in a small effort to right the balance between them, conscious that the case for the rights ethic has already (and frequently) been well and eloquently made elsewhere, and that both I and the reader need little further convincing that the concept and protection of rights in these issues is vital.

2. Rights in Medical Ethics. Some Opinions

There are of course philosophers and moralists who deny outright any useful place to the rights approach in some or all issues of medical ethics. R. M. Hare for instance (writing about abortion but clearly thinking of other issues as well) insists that the rights approach is unhelpful because, “. . . nobody has yet proposed an even plausible account of how we might argue conclusively about rights. Rights are the stamping ground of intuitionists, and it would be difficult to find any claim confidently asserted to a right which could not be as confidently countered by a claim to another right, such that both rights cannot simultaneously be complied with.”¹⁹⁸

Another view denies the usefulness of the rights approach not because of irreconcilable conflicts of rights, but because *needs* come first. Typical of this view is Joseph Fletcher, who writes (as already cited earlier): "The question is: which comes first, rights or needs? Do rights define which needs are to be recognized, or is it the needs that validate the rights? I believe that needs have precedence over rights; that is my ethical stance. Therefore to be candid and careful about this subject, I am not primarily concerned about any supposed right to life or supposed right to die; I am primarily concerned with human *need* — both of life and of death. This is my confession."¹⁹⁹

Still another, though similar view is that of Stanley Hauerwas, writing of biomedical research involving children, and the role of parents in decision-making. He maintains that the "rights language" does not provide the best ethical framework for the formulation of appropriate policy in this area. He proposes as a better basis than children's "rights", the concept of parental duties and responsibilities toward their children — that is, to love, protect and educate them. A child's needs, he argues, is not for "rights", but rather for trust, love and care.²⁰⁰

These views do not adequately recognize that for some purposes and contexts the rights approach might be useful and essential, even though inappropriate or at least insufficient in others. As well, they have an "either/or" flavour to them which this writer does not share. Let us now attempt to push the analysis a little deeper, in an attempt to sort out and evaluate the pros and cons of the rights and law models when used in ethical reasoning and policy-making. For much of what follows we are indebted to the analyses of John Ladd²⁰¹ on the ethic of rights, the ethic of responsibility and the notion of "ideal rights".

3. "There Oughta Be a Law." Moral Rights as Legal Rights

First of all one should attempt to clarify or define the terms, particularly the word "rights". The kind of "*rights*" I am primarily interested in are *moral* rights, that is rights claimed to be derived from sources other than courts, legislatures or other conventions. These latter are generally what we mean by *legal* rights or "positive rights". There are a number of different claims as to the source of moral rights — *i.e.* human nature, God, the divine will, moral principles and so on. The concern here is not to evaluate these claims, only to note the distinction between moral and legal rights.

Moral rights *may* be protected by being translated as well into *legal* rights, though they need not be; they are "potential" legal rights. On the other hand a just state will normally seek to the greatest possible extent to incorporate moral rights (though not all moral rights) into its processes and regulations.

But there are those who claim that because a moral right *exists*, there (obviously!) should be a *legal* right protecting it articulated in laws or legal rules. For instance, because (it is argued) there is a (moral) right to refuse treatment, or a (moral) right to die, there ought to be legal rules enacted by legislatures to recognize them. No doubt in some cases the translation from moral to legal rights is justifiable, beneficial and even overdue. I will note some examples shortly. But I will also note instances when this kind of translation might be out of place.

Whatever the case, this "let's make a law" reflex, this dovetailing of moral and legal concerns, often makes it quite unclear in discussions of our issues as to whether the commentator is concerned with *moral* issues, or with what kind of *laws* we should adopt. They are after all, different (though often related) perspectives, and each has to grapple with some considerations not relevant to the other.²⁰²

4. Coping with Impersonal Relationships and "Public Rules"

None of the above is to suggest that there are no good reasons behind the appeal of the rights or law model in these matters. There is a very real utility to this approach, and before proposing some reasons why it might be inadequate in some other respects and contexts, one should note the points in its favour.

In the first place legal relationships define and organize our relationships with both strangers and non-strangers. One may suddenly find oneself in an unexpected situation or place with total strangers, yet because attention has previously been given to the rights of anyone who finds himself in that place or situation, one's rights *can* be predictable and secure.

This point of course has immediate relevance to the medical context where in many if not most instances one may be in a strange hospital, and be cared for by total strangers including the physicians.

Clearly the concept of rights and its various expressions in the form of protections, rules and guidelines are useful for defining the patient/staff interaction. It is particularly important in this kind of context — impersonal relationships with a strange hospital staff for instance — that the laws and rules articulating rights such as those to informed consent and to refuse treatment, be clearly articulated and known by all parties.

Secondly, the law or rights approach also defines and organizes our relationship to *organizations* and *institutions* such as hospitals. One may have moral relationships with particular *individuals* in such institutions, which persons may relate to the patient with compassion and concern. But since *institutions* are impersonal, non-moral entities, the patient's relationship to them is normally defined in non-moral ways, that is, in legal or quasi-legal terms.

The usefulness of the rights approach in this context is that it provides us with a ready-made vehicle for coping with and making claims not only from impersonal institutions, but also from *professionals* such as doctors and others who may define their relationship with the patient largely in a legal manner as defined by their professional role. This latter point is extremely important in the medical issues we are considering inasmuch as,

... one of the most urgent and critical moral questions for modern mass industrial society is how to reconcile the moral responsibilities of individuals with the increasing power and authority of bureaucracies and other rule-governed groups, *e.g.* the professions. . . For it is clear that the fortunes, health, and even the lives of individuals are becoming increasingly subject to impersonal decision-making by officials and professionals who represent, *e.g.* hospitals, drug companies, and the medical profession. This decision-making, in turn, depends for its legitimacy and validity, not to mention its direction, on rules laid down by or adopted by organizations, *e.g.* formal and professional organizations, or imposed on them from without by legal authorities or by the market-place.²⁰³

In other words, since these institutions and professional associations define their own responsibilities and rights by networks of rules of all kinds based on the model of law, the only way the interests of patients and other individuals can be realistically and adequately protected against possible encroachments is by themselves making full use of the legal model, the rights model. In these situations, appeal to more personal considerations or simply to moral rights may be quite ineffective. What comes to mind here is the adage, "fight fire with fire!"

All of this is particularly to the point in dealing with what are sometimes called *public rules*, that is, rules and codes which organizations and professional associations formulate to regulate the conduct of their members in their dealings with each other and their clients. Strictly speaking they are not legal rules — not established by the state or its organs; they include all sorts of things, including social norms and “accepted practices”. But they are nevertheless “rules” in that they guide conduct and are enforced by sanctions. But they are often unwritten, and often more or less imposed on clients/patients without their knowledge or consent. An example of a “public rule” (sometimes a legal rule as well) is the generally unwritten rule that only doctors not nurses (without the doctor’s consent) may reveal a diagnosis or prognosis to a patient.

Public rules ought to be a major issue and concern in any analysis and reform of the “who decides, who controls” question. “Sooner or later, almost all of the issues relating to such things as euthanasia, the doctor-patient relationship, confidentiality and record-keeping, the initiation or termination of treatment, the operations of ICU’s etc., lead to questions about the public rules of organizations like hospitals or of the medical profession, *e.g.* questions concerning which rules ought to be adopted, changed, revoked, overridden, ignored, etc.”²⁰⁴

Another relevant consideration here arises from the fact that one of the properties of rules (at least in practice) is that one rule may override another; there exists a fairly recognized “hierarchy” as to which rules have relative priority in this overriding function. For instance, moral rules may override legal rules, and legal rules override public rules. Behind this function or concept seems to be the unspoken assumption that *only* a rule can override another rule (or only a *right* can overrule another right), and that therefore other factors such as motives, responsibilities, wishes and so on are logically unable to override rules (or rights).²⁰⁵

This is yet another reason why the appeal to rights can be useful — in impersonal contexts not open to reform by appeals to more personal considerations (particular needs, desires, compassion etc.), standing on one’s rights may be the only way to secure and protect one’s interest, especially if what is required is the overriding of another right or rule.

B. The Inadequacy of the Rights Model, the Law Model

So much for the utility of the rights model. But what makes it so at home in impersonal contexts, namely its own quality of impersonality, is precisely what makes it inadequate in contexts where relationships are, or could be, more personal, more open to considerations other than simply rules and rights.

1. Rights as Peremptory, Adversarial and Minimal

To make this point calls for a closer look at the logical properties of rights. As noted earlier, moral rights can be "translated" into legal rights so that they can be embodied in the form of a legal right; put another way moral rights are "potential" legal rights. That being so, it is safe to say that moral rights and legal rights have the same basic content or logical properties, and we can understand the role of rights in ethical thinking (*i.e.* moral rights) by studying how rights work in law. There are (at least) four properties of rights relevant here.

The first is the *peremptory* nature of rights. That is, they may be demanded peremptorily. One may use coercion in securing them, even for instance to the point of killing someone in the exercise of the right of self-defence.

A second property is the kind of relationship they typically represent between persons — that is a real or potential *adversary* relationship. The right-holder who has the right has it against someone, and he normally asserts the right reactively — that is when the right-owner does not respond to requests, needs and demands.

Thirdly, the right-holder *may exercise* a right he possesses, but the right-owner has *no such option* if the right-holder wants to exercise it. He must do what the right demands. As soon as we use the rights approach to decide what is to be done, the only relevant concern for the right-owner becomes the fact that the right-holder wishes or does not wish to exercise the right. No other moral considerations really matter — not compassion, not the fact that it might not be desirable for one or the other party, not the pros and cons of staying alive or dying.

Fourthly, the rights approach is a *minimal morality*. Rights create duties which the right-owner must perform, but the obligation is limited to those corresponding to the rights. He need do nothing more. If the right-owner does not do (or abstains from doing) what is required by the right he is condemned; but to fulfill the right does not mean he deserves praise or gratitude — he is only doing what is required, nothing more.

2. The Appeal to Rights as a Last Resort in Patient/Physician Relationships

If one situates these properties of rights in the medical context, one can hardly avoid the conclusion that using the rights approach alone or primarily would be quite inadequate. "An ethic of rights that limits itself to rights and obligations is obviously defective, for, on almost anybody's view, a considerable part of morality is left over after the rights-obligation component has been subtracted, for example, acts of good will, charity, etc."²⁰⁶

First of all, communication between patients and physicians need not be *peremptory*, that is backed up by some form of coercion, nor need the relationship become an *adversary* one. It may of course come to that, but surely that is a sign that (personal) communication has broken down or was never possible. It may then become appropriate and necessary to appeal to rights, because a potentially and ideally personal relationship has become or remained in fact, impersonal. The point here is simply that such an appeal should be seen as a *last resort*. To base a request only on the possession of a right, before or unless necessary, might express a lack of trust, and thus risk whatever personal communication or relationship may have been possible. *Possession* of rights is not in question here, nor is the fact that rights form an important substructure in medical decision-making.

Rights are generally appealed to more readily (and the adversary relationship is more typical) with strangers than with those we are close to such as family and friends. But certain situations or states tend by nature to be very personal, very private, and the kind of relationships particularly needed at that point are close, personal and understanding ones. One such state is that of dying, and one group with whom one needs that kind of relationship is the medical staff. For anyone, patient or staff member, to determine whether and how to treat more or less exclusively on the basis of rights would be to risk turning this very private and personal experience and relationship into an adversary and public one.

Yet the rights approach alone very often appears to be appropriate inasmuch as dying itself has become increasingly institutionally and bureaucratically controlled. Too often dying is treated as if it is an impersonal experience, in which personal care, compassion and individual needs are more or less secondary. Happily there are some currents moving in the opposite direction as well, such as the Hospice Movement,²⁰⁷ and the relatively recent and sensitive attention focused on death and dying by people like Elisabeth Kübler-Ross.²⁰⁸

As for the third property of rights referred to above (that the right-owner must do what the right demands as soon as the right-holder exercises the right), it too suggests the inadequacy of using the rights approach alone in medical decision-making. In many of the more important and difficult issues rights are best *not in fact exercised* by any of the parties involved. Patients and physicians would find helpful communication and decision-making extremely awkward if as a general rule, the patient chose to exercise his right to refuse treatment, and the physician his right to refuse to treat. That is not to say that it might not sometimes become necessary, even advisable, for the patient or physician to exercise their respective rights. But if a right *is* exercised by a right-holder, then (if rights were the only or major consideration) the right-owner might be put in the position of having to commit on occasion an irrational or immoral act measured by standards other than rights.

Lastly, even the *exercise* of a right may itself be immoral, even when one really does have that right. Consider for instance the case of someone in need of blood or an organ. Someone else may have the *right* to refuse to provide it, but by other standards such as close relationship, or compassion, not to provide it could be immoral. "Sometimes considerations based on compassion, humanity, or a personal relationship of some kind may provide more appropriate reasons for a decision than a reference to rights."²⁰⁹

As for the fourth property of rights, that of being a "minimal morality", it too points to the inadequacy of a rights ethic alone in the medical context. What of all the other elements of morality which do not fit under the heading of rights? It is usually argued that this other large part of morality beyond rights (*i.e.* compassion, charity, etc.) comprises "acts of supererogation", acts "beyond the call of duty."²¹⁰ This division of morality into a mandatory part and an elective part may well be tenable when dealing with strangers, but it appears quite deficient in the context of personal relationships. And because of its intimate and caring nature it seems appropriate to

include the doctor/patient relationship in the category of potentially and ideally personal relationships.

According to rights theory then, one would have to say that when a physician makes a special effort for a patient he is either responding, out of *obligation*, to a patient's right, or doing it as an *extra favour* to the patient. But one is inclined rather to resist classifying such conduct in either way, "... for in contexts like this, optimum as contrasted with minimum concern, is neither something that the patient is in a position to demand peremptorily as a right nor is it simply an extra kindness on the part of the doctor."²¹¹

C. An Ethic of Responsibility

1. A Comparison with an Ethic of Rights

If the rights approach has limitations when used in a context of personal relationships, are there approaches which go further? One such is what could be called an *ethic of responsibility*. It attempts to identify the *moral* duties which arise from interpersonal relationships, and groups them under the concept of responsibility.

The kind of duties this ethic posits are not those which can be demanded as rights, that is, peremptory rights, but rather those more linked to *virtues* of some sort, more or less the same acts which rights theory calls "acts of supererogation"; but in this context they are not choices, extras or just acts of generosity, but comprise a central element of the interpersonal relationship itself. Within that relationship they are responses to the recipient's *need* and are attempts to do what is best for the other person.

The key to this ethic of responsibility then is the relationship. As Ladd notes: "By 'responsibility' I mean a concern that a person ought to have for another person's welfare by virtue of a special relationship that obtains between him and the other person. Under welfare should be included such things as a person's security, health, education and moral integrity."²¹²

There are a number of ways in which an ethic of responsibility differs from and goes beyond an ethic of rights. First of all, an ethic

of responsibility can (and must) accommodate and consider a great number of factors of benefit to the patient in coming to a decision; for instance, risks and benefits, other relationships which might be affected, and so on. And the decision itself is an act of *weighing* and balancing many things in the course of thought, consultation and dialogue. But an ethic of rights bases the decision exclusively on the existence and status of the right. No other matters are relevant.

Secondly, *attitudes* such as concern and caring are central to an ethics of responsibility. Such attitudes are almost the definition of moral responsibility. But in an ethics of rights, attitudes and motives really don't matter.

Thirdly, an ethic or relationship of responsibility is able to acknowledge and cope with a degree of *inequality* between the parties concerned. One has need of help, the other is able to help; one is dependent, the other is not. But a rights relationship presupposes an equality between them, often more fictional than real. Clearly in the medical context the responsibility relationship is usually a better reflection of the realities of the situation than is the rights relationship. After all, patients are generally more or less dependent on and in need of the physician and often too helpless to assert their rights. All the more is this so with newborns and comatose patients.

It could be argued that the promotion of an ethic of responsibility increases the danger of paternalism. In medical decision-making there is always of course the risk of paternalism. But surely that risk is rooted more in the patient's dependence itself than in whichever ethic is called upon to cope with it. *Acknowledging* the dependence and inequality is not the same as *encouraging* it. On the other hand dependence of the patient on the doctor *need not* be or imply paternalism — any more than the relationship between teacher and taught *must* be paternalistic.

To stress here this state of dependence and need as well as an ethic of responsibility is not at all to imply that patients, including newborns and comatose do not *have* rights — only that though they do, they cannot always be readily asserted. In my view it remains true that competent, incompetent and non-competent patients have essentially the same rights, and that if ever a physician's paternalism endangers the rights of a patient, then appeal to those rights by the patient or a proxy is in order.

The notion of *proxy* decisions by a family member or patient's agent in this kind of case is the solution of the rights ethic to the obvious inequality between parties when one is incompetent. It is of course a useful and necessary manner of protecting rights and interests. But insofar as the use of proxies is seen as the *whole* solution to the problem in such cases, as if that is all there is to say, then the rights ethic has ignored a large part of the reality.

For with or without the involvement of a proxy, the fact remains that this particular patient vis à vis this particular doctor and staff, remains dependent and unequal in terms of needs and communication. And decisions about rights, whether made by the patient or by proxy, cannot in reality completely wipe out that dependence, or be a substitute for the continuing day to day care and interaction focused around dialogue and needs, as acknowledged by an ethic of responsibility.

This ethic acknowledges a basic *equality* in terms of worth and dignity, at the same time as an *inequality* in terms of need. Therefore it can seek to gear help to real needs, rather than stop short at the fulfilment of formal rights requirements based on a fictional equality (in ability), rather than an actual inequality (in need). "In other words, persons morally responsible for others should treat them as ends and not as mere means — *all the way through*, as it were, and all the time, rather than just partially and occasionally as is usually the case when morality is reduced, *e.g.* to contractual relations."²¹³

A final difference between the two ethics is that in the case of an ethic of responsibility the relationships are *dynamic*, whereas in an ethics of rights they tend to be *static*. Consider once again the two ethics applied to the doctor-patient relationship. Because the former ethic (responsibility) weighs many factors and comes to judgments via consultation, debate, dialogue and persuasion, and because it seeks to adapt care to real and often changing needs, there can be a mutual and evolving teaching and learning.

Explanations and discussions of diagnoses, prognoses, treatment options and risks and benefits, are all opportunities for the physician to better know and care for the patient, and for the patient to better inform and influence the physician, as well as better understand and cope with his own condition. If the relationship is in fact responsible, and neither impersonal nor paternalistic, there will normally be changes in both parties.

But because the ethic of rights is concerned with rights in place before any decision-making begins, mutual growth and accommodation could be more discouraged than encouraged by the univocal or predominant use of the rights approach. That said, one should not imply that the two ethics are opposed or mutually exclusive. They are instead complementary, and both are absolutely essential.

2. Its Relevance for Law Making and Health Care

(a) *The "ideal" of objectivity and detachment*

There is an important lesson and relevance for both *lawmakers* (or law reformers) and *health care personnel* in these observations about the ethic of responsibility and its "anchor" in interpersonal relationships. What occasions the lesson and the relevance is the very high marks both groups are being increasingly urged to give to *objectivity* and *detachment*.

Consider to begin with the trend, argumentation and priorities in many recent biomedical legislative proposals or enactments, as well as court decisions. To a large extent the normative assumption is that, "the ideal health care decision-maker is 'objective', 'rational', 'detached' . . . Accordingly, the argument runs, it is appropriate in these situations to have the decision made by an outsider who can more closely approximate the detached and rational ideal — a judge, that is, who guides his decisions by public norms in law."²¹⁴

To some extent this assumption and the reforms based upon it are justifiable and long overdue. But to the extent that it represents an excessive and univocal use of the "rights ethic" it may suffer from the same exaggerations and deficiencies we suggested above for the rights ethic itself.

One of the areas in which this assumption is most evident is the issue of parental decision-making for the medical care of children. Traditionally (though with some exceptions) it was left to parents to decide these matters. But increasingly legislatures and courts are insisting that the proper place for these decisions is the courts, and that the child should be represented by an independent third party. The grounds for these arguments are that parents tend to be "ambivalent" about the interests of their children, that their own interests may conflict with their children's, and therefore they are not really the ideally objective, detached decision-makers required.

To avoid these conflicts of interests, and to assure "equal justice", a justice "of laws not men", and the "treating of like cases alike", a judge replaces the parents, uses impersonal standards of judgment, and most importantly (from our point of view) judges are told *not to identify* with the litigants.

In this view the good parent is the one who can deal with children dispassionately, expertly and completely objectively as a sort of "professional child-rearer", fully respecting their rights and individuality. That being the case (it is argued) it is right and natural that in cases where a parent is most likely (under stress) to be "subjective", the state should intervene to supervise the decision-making and if necessary to enforce a child's rights against the parents. No wonder then that, "This normative valuation of parental objectivity, of the 'good parent' as the expert applier of the best considered rules for childrearing, readily suggests the essential interchangeability of parents and judges. The 'good parent' that is, behaves like a 'good judge', and therefore a 'good judge' can easily — indeed interchangeably — evaluate what a 'good parent' would do in any particular circumstances."²¹⁵

Much the same is urged for doctors. The "detached and objective" approach means that the physician should abstract from patient values and other particulars and in a computer like manner simply concentrate not on the patient as person, but the patient as symptoms, disease and treatment. In a sense the psychiatric model is the model for this perspective in other branches of medicine as well. The primary injunction to the psychiatrist is to avoid personal relationships and identifications with patients in order to remain detached and free of conflicts of interest.

Not of course that such standards of "objectivity" are realistically possible for either judges or physicians. There are deviations. "But these deviations are not seen as occasions of self-congratulation, as virtues to be pursued, but rather as errors to be corrected, perhaps by appeal to a higher court or by recourse to a more certain diagnostic technique, or — if the highest court or best available technique has ruled in the matter — as errors to be tolerated for the moment, but without pride."²¹⁶

(b) *The limitations of detachment in medicine and law*

But not only is such total detachment, such scientific objectivity not *possible* between for instance parents and children or physicians

and patients; more to the point it should not always be seen as *desirable* or as a deficiency necessarily and always requiring correction by law.

It is only in relatively recent times, (especially since both Freudian teachings, and the ethos of objectivity in science became normative), that profound bonding and identification between parent and child, or the less intense but just as real relationship between physician and patient have been called problems rather than facts. There is no doubt that new biomedical technologies and complications require in some instances the creation or reform of legal rules and processes to determine duties and obligations. But on the other hand, to a large degree there may be *more protection* for the child and the patient in the close personal interrelationships, the "confusion of selves", the lack of detachment between parent and child, or patient and doctor, than in recourse to legal or judicial "objectivity."

Surely this is the experience and the intuition behind the growing awareness that while scientific medicine has had and will continue to have its triumphs, nevertheless its overly mechanistic approach based on the method of scientifically detached observation, may largely have lost sight of the patient as person. This generally held view at least suggests that the older tradition of identifying and personally relating with patients, was more successful in treating and caring for the whole person.

There are other indications as well that the more one separates oneself, detaches oneself, both physically and emotionally from one's clients (or victims), the more one is able to depersonalize them and detach oneself from one's own decisions. The result can hardly fail to be a greater likelihood of insensitive and even inhumane responses to the needs of others.

Obvious and extreme examples were the Nazi atrocities (some of them medical in nature) during the Second World War, or the experience of bomber pilots who never saw their victims. In each case observers have remarked on the surprising emotional detachment of the actors from the decisions to do what was done. The standard defence involved assigning the responsibility to another level ("I was only obeying orders"), and included a large degree of self-deception. Their "I" was not really involved, the decision was someone else's; whatever they might have thought of the morality, they were only "instruments" and not responsible.

The point is that to disregard and undervalue the traditional bonds, relationship and identification between patients and physicians risks decisions which are insensitive, inhumane and not to the patient's benefit. By "detaching himself" from any identification with the patient, as many actual or proposed legal rules encourage him to do, the physician may increasingly accept and comply (in the name of patient autonomy) with patient requests which he is convinced are harmful and non-beneficial.

Whereas previously he may have argued and attempted to persuade the patient to the contrary, realizing (or at least suspecting) the patient's wish to die was probably temporary and not fully rational, by suppressing his identification with the patient he may now accede too quickly. No doubt there were (and are) abuses in the other direction. Physicians have been known to be so paternalistic and identified with their patients, that patient wishes contrary to their own were simply ignored. But now overzealous obedience to or fear of the law may well lead decisions in the opposite, and equally harmful, direction.

Aided by his legally encouraged detachment and objectivity,

... when the patient requests death from a doctor schooled in this new regime, the danger is that the doctor will comply with great vigor and haste, and even moralistic self-righteousness. He will do so in order to keep intact the rigidly separated roles prescribed for each, in order to reassure himself that he is not the patient, to reassure himself that he does not feel the terror and pain that the patient feels, to reassure himself that he will not die because it is only the patient who will die.²¹⁷

The same possibility for insensitivity and self-deception may exist in too frequent recourse to court decisions.

When a judge supervises parental decisions, and thus accepts apparent responsibility for the decision whether a child should donate his kidney to a sibling or whether a comatose child's respirator should be disconnected, the judge can act with the comforting knowledge that he and this child are quite separate from one another — that the child is not his, that the consequences of this decision will not shape his family's life and his self-conception forever, that he is after all only applying 'the rules' with an impartial eye or even, as the popular image of Lady Justice suggests, with blindfolded eyes. The parents and doctors can also reassure themselves with this same false comfort — that they are not personally responsible for their actions toward the child, but that someone else accepts that responsibility — someone who... himself disclaims any personal responsibility for his actions.²¹⁸

D. The Notion of "Ideal Rights"

1. Ideal Rights as Non Proprietary

But if the somewhat legalistic "proprietary model" of rights which we have been considering is by itself incapable of accommodating some of the many considerations noted above, is there perhaps another kind of right more able to do so? In a sense the notion of *ideal rights* is an alternative to the model of rights or of law, one which stands on its own; but in another sense (as Ladd observes) it translates into a sort of "rights language" most of the elements of the ethic of responsibility.

To a large degree it is the "proprietary" nature of rights which accounts for their inadequacies in the medical context. Our property tends to be something we keep all to ourselves. We do not have to account for it to others, and its possession more readily encourages attitudes of defensiveness and selfishness than trust and compassion. Not that the proprietary or legalistic notion of rights does not remain useful. It does. As I have several times indicated, that notion of a right, especially in the more impersonal contexts, and at least as a last resort, remains essential.

"Ideal Rights" correspond to what some have called "welfare rights".²¹⁹ They are different from proprietary rights in a number of respects. We will consider some of those differences, and then apply the notion of ideal rights to "rights" such as the right to life and the right to die. The first is that instead of *rules*, which tend to be black and white, they represent *principles*, which as we saw in discussing the sanctity of life principle, tend to be somewhat vague and flexible. They are more in the nature of guidelines than absolute norms of conduct.

They are more rights *to* something than rights *against* someone. They deal with things society, the government or institutions ought to provide and respect — the sort of rights formulated in the U.N. Declaration of Human Rights. As such they would involve such things as the right to health, the right to education and so forth.

They are called "rights" (instead of "needs" or "social goals") because of their peremptory nature; that is, they may be demanded, sometimes even by the use of coercive power. One is in a real sense

a "right-holder" of these rights, and the "right-owers" (government leaders, physicians, etc.) "owe" these rights not just thanks to their "good will". The obligation they impose is not on any individual, but on individuals as members of society. The right to health care for instance creates an obligation for *society*, not for an individual physician.

And lastly, they require affirmative action, not just abstention from an action. Inasmuch as they are rights to the means necessary to live a good life — including the *morally* good life — they require the "right-owers" to establish policies and priorities which will make that possible for its citizens, members or clients.

2. Right to Life and Right to Die as Ideal Rights

Measured against these criteria, both the "right to life" and the "right to die" could best be called, "ideal rights". Without the necessary elements asserted by these rights, a fully moral life is impossible. Obviously life itself is necessary if a moral life is to be possible. And the "right to die" (at least understood as the right to be allowed to die) would also seem to be a necessary ingredient for a moral life. Dying is after all a moral act, and even though one does not choose death as an end (euthanasia) one should be allowed to express one's moral ideals by having the right to "control" one's death, at least to the extent of dying a good death if at all possible.

Since ideal rights relate to *moral* needs, if the end is immoral, the claim is invalid. These rights are different in this regard from strict rights, the exercise of which depends only on the choice of the right holder. In other words, if the manner and purposes involved in a person's claimed "right to die" are judged to be immoral or capricious, then society need not permit or help that person.

As an "ideal" right, the right to die creates an obligation for society, rather than for individuals. The right to die as a "proprietary" right (it could be argued) might impose a correlative duty on a physician (for instance) to *assist* the right-holder in the exercise of that right, that is, to kill the patient. "If the claim were verified that an individual has a right of arbitrary self-determination in the matter of life and death; then if he chooses to live, there is a duty upon others to protect his life and, equally if he chooses to die there is a duty upon others to assist his dying. . . ." ²²⁰

But if, as has been argued in this paper, killing (i.e. euthanasia) is not morally justifiable, then its choice by a patient cannot impose a duty on anyone else, and it cannot therefore be called a "right". But as an "ideal" right, the expression "right to die" can be morally justified and does point to an important correlative obligation created for society.

Society's obligation with regard to the right to die is to ensure the conditions and processes (*i.e.* in the law, in the health care system, etc.) which will facilitate peoples' control over their own death, and as much as possible in accordance with their own consciences and wishes. Obviously that is no simple task as it involves long and serious attention to the formulation of priorities, guidelines and law reforms which attend to (among many other matters) the sorts of sanctity of life/quality of life issues raised in this paper. Law reforms and court cases will obviously have a large role to play in that task.

E. Conclusions: Rights, Responsibility and Quality of Life

(1) In conclusion, it is no doubt obvious to the reader that both the "ethic of responsibility" approach and the closely related notion of "ideal rights" are helpful and important confirmations and expansions of the earlier analyses of quality of life.

(2) All the conclusions of those quality of life analyses implied exactly the kind of context and priorities associated with an ethics of responsibility and with ideal rights. That context is one of interpersonal relationships, the ethic is that of responding to both needs and rights and goes well beyond where (proprietary) rights end. It is difficult to conceive of an evaluation and decision involving quality of life and related criteria (such as patient benefit, patient wishes, minimal ability to experience and relate, useful treatment, the reasonable person standard, allowing to die with care, and so forth), except in a context of personal interrelationship and identification, rather than detachment and mere scientific objectivity.

(3) Earlier it was argued that patient wishes and patient self-evaluation should ultimately be decisive in treatment decisions involving quality of life factors. But if those who care and those who treat were detached and separate from *this* patient, or unwilling to

identify with him, they could not really *know* his needs, wishes, and self-evaluations; nor would they be in a position to understand and interpret those wishes, and sometimes attempt (by discussion, not duress or lies), to change the patient's mind if they feel the choice is capricious and non-beneficial.

(4) It was also argued that quality of life criteria related to life and death decisions cannot be reduced to one single factor or to simple predetermined definitions. It is more a matter of *weighing* many factors, with some flexibility, and specifically applied to *this* patient. And as we noted above, the need to judge a wide range of considerations is a central characteristic of an ethic of responsibility. Quality of life decision-making therefore goes well beyond an ethics of rights and is closer to an ethic of responsibility.

(5) It was also suggested that for incompetent patients, the "reasonable person" standard is viable and justifiable in decisions to initiate, continue or cease life supporting treatment. In the ethics of responsibility we find encouragement to use this norm not in a scientifically detached manner, but from within a relationship of *identification* with the patient, and by asking what *we* would want done if in that position.

(6) And finally attention was drawn to the continuing obligation to *care* for patients, no matter what treatment decisions are taken. To care for the dying patient means to accompany that patient with comfort and support. From the perspective of the ethic of responsibility this caring is rightly anchored in the bonds one has, or should seek to have, with the dying patient, bonds of identification and compassion that should be strengthened not weakened; and as long as care for the dying remains depersonalized and oriented only to the minimum morality of an ethics of rights it will remain the impersonal experience it too often is.

(7) What all these considerations suggest is that the *context* in which, or the perspective from which, quality of life considerations are dealt with, is at least as important as the "who controls", "who decides" question alone. From the perspective of an ethic of responsibility the fundamental questions are, "who needs help?", "what help is needed?", and, "is the relationship between helped and helper a close interpersonal one?".

PART III

SOME RECENT PUBLIC POLICY GUIDELINES AND PROPOSALS - HOW THEY MEASURE UP

In this final section I will take a brief look at some guidelines, policy proposals and decisions which have either to some extent incorporated and highlighted the views and priorities defined in this paper, or which, in some respects at least, have gone in a different direction. This will be only a survey of some few samples of the many available, in order simply to demonstrate that the issues raised earlier have practical and urgent relevance to actual decision-making in medicine and law. Some proposals in only five of the many relevant issues will be described and briefly evaluated. The first is that of hospital guidelines for the terminally ill, the second is that of courts and incompetent patients, the third is that of termination of treatment for seriously defective newborns, the fourth is that of allocation of scarce resources, and the fifth is that of Natural Death legislation, or "living wills".

Chapter 7

Hospital Guidelines for the Terminally Ill

I will refer to only two of the several such guidelines proposed recently. One is the set of guidelines drawn up by a group from Beth Israel Hospital in Boston, and the other was drawn up for the Massachusetts General Hospital, also in Boston, both in 1976.²²¹

The first point to be noted about these guidelines is the simple fact that they were formulated and publicized at all. That alone, in the words of Charles Fried, "... is an event of the first importance."²²² Earlier I observed that these "public rules" in hospitals are too often formulated in secret and simply imposed on patients. Sometimes patients are not even aware they exist. And for this particular subject — standards for the care and termination of treatment of the terminally ill, most hospitals apparently have no consistent and consistently applied, much less public, guidelines at all.²²³ Therefore the promulgation, and public discussion and knowledge of such policies is a welcome step towards a standardization of norms and providing of essential information to the patient.

Also helpful and unusual is the acknowledgment in both guidelines that patients in some conditions and under some circumstances *are* allowed to die, and always have been. What is new is an attempt to develop predictable procedures based on a classification of patients according to the probability of their survival, in order to allow for planning ahead on the part of both staff and patients, and to help reduce staff conflict and anxieties in these matters.

For instance, the Massachusetts General Hospital policy classifies critically ill patients according to the probability of their survival in this way:

- Class A: "Maximal therapeutic effort without reservation."
- Class B: The same as A, but "with daily evaluation because probability of survival is questionable".
- Class C: "Selective limitation of therapeutic measures." In such cases, there could be orders not to resuscitate, a decision not to give antibiotics to cure pneumonia and so forth.
- Class D: "All therapy can be discontinued." This class is usually only for patients with brain death or those with no hope of regaining "cognitive and sapient life."

Hopefully and most importantly the standards and decision-making processes proposed by such guidelines will in the final analysis put the *patient's* benefit and decision-making rights in first place. As argued earlier, the patient centered perspective and benefit provides both the only justification for ceasing treatment, and the best protection against intrinsic quality of life considerations sliding into "social worth" or other utilitarian considerations. The competent patients should make these decisions themselves; whereas for incompetent patients, the patient's agent, using the "reasonable person" standard should make the decision on the patient's behalf. Fried has asked the right question therefore, in writing: "To my mind the most important question is this: At whose good are these new statements aimed? Are they aimed at freeing the patient from the tyranny of a technologic (or bureaucratic-professional) imperative to keep alive at all costs. . . Or are they aimed at freeing society from the burden and expense of caring for a growing multitude of extravagantly demanding moribund persons?"²²⁴

By general admission, the guidelines may well be deficient, or at least unclear, on this score. The Massachusetts General policy is especially troublesome in this regard. It focuses most of the attention on the roles of the physician and hospital staff, but gives relatively little importance to the rights of the patient and the family. It has many of the symptoms of the "missing patient" syndrome, in apparently assuming that ultimate responsibility for decision-making falls upon the physician rather than the competent patient. On the other hand the Beth Israel policy does focus on the right of the patient to make decisions about his care. It calls for the establishment of a committee, but its role is mainly that of determining an

accurate prognosis as to the imminence of death. Once that prognosis is made, the actual decision-making shifts back to the patient and family.

One is left equally uneasy when it comes to the *incompetent* patient in these guidelines. For reasons already referred to earlier, parents are the most appropriate decision-makers for minors, and other family members (or guardians) for incompetent adults. Karen Quinlan's father for instance was judged by the court to be her most appropriate guardian. But in these guidelines all these people are more or less excluded from decision-making. The Beth Israel guidelines do include them, but one is left uncertain as to whether the review committee or the family would prevail should there be a disagreement.

Is the patient's perspective primary in these guidelines? One fears not — at least not primary enough. What compromises that perspective somewhat is the blurring of the distinction between the medical and the moral dimensions in these decisions to cease treatment. Both are important, but, "... the decision to terminate or continue treatment is basically a moral or religious one. . . By emphasizing the role of the physician as decision-maker, with the family as legitimating or acquiescing body to what is conceived as basically a medical decision, this distinction is lost. And when it is, the primacy of the patient's interest is negated."²²⁵

Particularly in the case of the Massachusetts General guideline, one has the impression that the primary goal of the guidelines was the achievement of greater staff unity and mutual support, a very worthy goal. But it should not be the primary goal, nor should it be assumed that if such unity and standardization is achieved that will in itself, and inevitably, ensure the promotion of the interests and benefits of patients. "Guidelines can be useful if they are intended to provide a means by which patients and families can obtain information, make decisions, and ensure that their decisions are respected. But if they are primarily intended to reinforce the authority of the physician and to allow the patient and family at best a consultative role, they serve only to legitimate the physician's traditional paternalistic role and minimize the patient's autonomy."²²⁶

There is of course another side, another view, which deserves to be heard as well. It is a view with which one should have some sympathy, namely that the very introduction of guidelines and committees might only further complicate and institutionalize an

exceedingly sensitive and personal experience already too depersonalized and bureaucratized. The same hesitation was expressed earlier in this paper in the discussion of rights. One (perhaps too strong) expression of this view is this opinion of a surgeon, "... official guidelines will benefit only lawyers and administrators, while making it infinitely more difficult for physicians to do for the dying what most of them have been doing all along."²²⁷

Agreed. Under ideal conditions, assuming personal relationships between physicians and patients, assuming the physician knew beforehand the wishes and values of his comatose patient, and assuming the patient knew the physician's values and treatment policies, then guidelines and committees (just as the resort to the claiming of rights) would not be as necessary. But given the impersonality of many patient/physician, patient/staff relationships, as well as the variety and unpredictability (from the patient's point of view) of individual physicians' cessation of treatment policies, guidelines and committees have probably become a (perhaps regrettable) necessity. But only if the patient's interests are put first can they be a step forward instead of a step backwards.

Chapter 8

Courts and Incompetent Patients

Let us now turn to the consideration of a recent and extremely controversial court decision, namely the "Saikewicz" decision of the Massachusetts Supreme Judicial Court.²²⁸

First of all the case facts. The patient was a seriously mentally retarded man of 67, Joseph Saikewicz. He was able to communicate only through gestures and physical contact, and had been in a state school all his life. His I.Q. was ten, and he had a mental age of approximately three years. He was diagnosed as terminally ill with leukemia, but not in pain. The only treatment known to be effective is chemotherapy, which offered only a 30 to 50 percent chance of remission for a duration of from 2 to 13 months. The pain and other side effects of the treatment would be severe, the patient would be unable to understand what was happening to him, would not be able to cooperate in the treatment and might even need restraint. The school was unsure of what to do, and his only relatives (two sisters) did not want to become involved.

The superintendent of the school therefore petitioned the Probate Court for a guardian to be appointed, which the judge did. The guardian recommended that treatment would not be in the patient's interest, and the Court agreed. The grounds for the decision were essentially, the patient's age, the side effects, the inability to cooperate with treatment, the low likelihood of remission, the pain, and the quality of life possible after a remission. The decision was appealed, and the Supreme Judicial Court affirmed the

decision, adding that a full opinion would follow later. In the meantime Saikewicz died peacefully and painlessly of pneumonia. A few months later the Court's full opinion followed (in Nov. 1977).

The opinion dealt essentially with three points. They are: the *right of anyone*, competent or incompetent to decline potentially life-prolonging treatment; the *legal standards* controlling the decision as to whether potentially life-prolonging (but not life saving) treatment should be provided to an incompetent person; *procedures* to be followed in arriving at the decision. I will limit my comments to just a few of the many issues raised and considered by this decision, and deal with them largely from the perspective of the normative criteria argued for earlier in this paper.

First of all, the positive aspects of the decision. There are two points which (in my view) merit approval. First of all there is strong insistence by the court that both competent and incompetent patients have substantially the same right to decline potentially life-prolonging treatment. As regards *incompetent* patients this might be the clearest and strongest such assertion of patient autonomy and dignity to date.²²⁹ This assertion merits unqualified approval, in view of the dignity and autonomy it recognizes in all patients.

Secondly, the court adds a (theoretically) helpful and very "patient-oriented" qualification in deciding for a more specific standard than the "reasonable person" standard in resolving cases involving incompetent patients. The court set as its goal, to "determine with as much accuracy as possible the wants and needs of the individual involved." Because it puts patient self-autonomy first, it seeks to replace the "objective" reasonable person standard with the "subjective" test of the "substituted judgment". By this test courts and juries are not to ask what reasonable persons would do in these circumstances, but what *this patient* would have done.

Applied to Saikewicz, who would not understand the pain of chemotherapy treatment, he should be compared to a *competent* person who is informed that something painful will be done for a long time for reasons he won't understand and won't be told. Applying *this* test, as the Court did, it ruled that the factors against treatment outweighed those in favour.

One can only agree that in principle and from the moral and patient-centered perspectives this position of the Court could represent a new and added sensitivity to the particular needs and benefits of individual incompetent patients. Yet two reservations

come to mind. First of all, how often is it really possible to make a reliable "substituted judgment", especially perhaps by courts, since they tend to value so highly objectivity and detachment? Knowing what a *particular patient* would have wanted is no easy knowledge for anyone, but if anyone is likely to know, surely it is those closest to him, especially the family and sometimes the physician as well, but least likely an "objective and detached" court. But as we will see in a moment, family members are to be more or less replaced by judges in such decision-making.

But whoever is to make the "substituted judgment", it simply is not as easy or as certain a task as the Court seems to assume. After all, even when dealing with a fully competent person, whose behavioural signs are presumably conscious and reasonably accurate translations of his wishes and experiences, these latter are seldom fully transparent to another. We can have a "more or less" idea, but each person's way of experiencing is as unique as his personality and particular circumstances. How much more difficult still (if not impossible) is substituting judgment or "seeing things as another sees them" when it is a never-competent and non-communicative person under consideration.

Secondly, is there really that much difference in practice between the (objective) "reasonable person standard" and the (subjective) "substituted judgment test"? After all, the reasonable person standard attempts to determine what reasonable persons would do in *these circumstances*. Is that approach likely to produce a different conclusion than asking what *this patient* would have done? One wonders. Consider again the Saikewicz case. Surely one of the "circumstances" a court would (or could) weigh using the reasonable person standard is the fact that Saikewicz would not understand the pain or the reasons for the therapy, and could conclude that a *reasonable person* faced with protracted, painful, unexplained and incomprehensible therapy of doubtful success would refuse that treatment.²³⁰

Let us now consider two further positions of this court. The first concerns the court's understanding of the meaning and role of "quality of life". On this point the court appears to be both confusing and self-contradictory. In a rather unclear statement it asserted that, "to the extent that this formulation equates the value of life with any measure of the quality of life, we firmly reject it." The statement seems to refer to Saikewicz's mental retardation, and to be asserting that a mentally retarded person is worth saving. It went on to grant that it is correct to use the term "quality of life"

(as the probate court did), for the pain and discomfort which would be caused by the chemotherapy treatment.

The court's view is at least confusing in that it appears to assume that quality of life considerations (at least when they deal with patient conditions such as mental retardation) will tend most of the time to go against preserving the patient's life. Clearly, as this paper has argued, this need not be the case. Weighing *only* Saikewicz's condition or "quality" of mental retardation, one could and should conclude, with the court, that because he had at least a minimal ability to experience and relate, that quality of life test (alone) did not justify the non-initiation of treatment.

But not only does the court's formulation in this regard seem to assume the reductionist or "optimal life" meaning of quality of life in rejecting it, but it *does* in fact weigh his quality of life (i.e. mental retardation as well as pain) in deciding against treatment. It was after all partly due to his inability to cooperate with the treatment and to understand it (because seriously mentally retarded) that the "substituted judgment" test used by the court led it to conclude as it did. It therefore appears to be somewhat self-contradictory. I do not maintain that the condition of serious mental retardation *alone* argues for non-initiation of treatment, but only that (as the court itself did) it should be weighed along with the other conditions.

What is particularly unfortunate is the possible implications this assertion might have (at least in the U.S.) for medical decision-making generally when it comes to weighing similar factors. "This ruling could mean that brain damage to an infant, or very serious burns and disfigurement and limited bodily functioning, could not be taken into consideration in offering or withholding resuscitation or intensive care to a patient."²³¹

A second point which merits disagreement (as it has by many commentators), has to do with the *procedures* proposed for resolving this kind of issue. In effect the court ruled that the question of whether to continue or withhold potentially life-prolonging treatment was for the *courts* to decide, and not any other group. The following citation well conveys both the tone and the substance of that particular ruling:

We do not view the judicial resolution of this most difficult and awesome question. . . as constituting a 'gratuitous encroachment' on the domain of medical expertise. Rather such questions of life and death seem to us to require the process of *detached but passionate investigation* and decision that forms the ideal on which the judicial

branch of government was created. Achieving this ideal is our responsibility and that of the lower court, and is not to be entrusted to any group purporting to represent the 'morality and conscience of our society', no matter how highly motivated or impressively constituted. [Emphasis added]

If one believes that law and courts should be involved in these matters only as a last resort, then obviously such a belief is diametrically opposed to the position of this court. There are three points worth noting about the decision before making a brief comment. First of all, it explicitly and substantially disagrees with the Quinlan court decision, in that the latter entrusted the decision as to whether to continue artificial life support to the patient's family, attending doctors and a hospital ethics committee. Secondly, the Court appears to reserve to itself both kinds of decisions — those which decide to initiate or continue treatment, as well as those decisions against treatment. Thirdly, it is proposing that as a *general rule*, and not just in cases of conflict, the court and no one else should make these decisions. The advice of parents and others would of course be sought and heard by courts, but it would not be decisive.

As was already argued earlier, one need not believe as does the Court, that "detached but passionate investigation and decision" of the courtroom is necessarily (at least in the first instance) the best stance from which to decide these issues. Nor need we agree with the strongly implied bias against the likelihood of families, physicians and ethics committees contributing to responsible decisions made in the interest of the patient. George Annas (a Professor of law and medicine), in commenting on the case has expressed a view similar to this court's, though still more explicit. "A correct resolution. . . is more likely to come from a judicial decision after an adversary proceeding, in which all interested parties have fully participated, bringing in all their own perceptions, beliefs, and biases, than from the individual decisions of the patient's family, the attending physician, an ethics committee, or all these combined."²³²

One cannot fail to note in that view the assumption already noted above in discussing rights — that family members (and physicians) are by definition, too close, too identified with the patient, too "biased", to be capable of responsible decision making.

But another legal writer (Willam Curran), takes issue with the reasoning of the court and of Annas in this respect. And this for four reasons:

1. It misunderstands and mistrusts the role and ability of the medical care system to deal with these issues with both equity and sensitivity.
2. It assumes these decisions of ethical groups (or families) are not appealable to the courts when there is disagreement or suspicion of abuse. They are of course appealable.
3. Hospital committees for the most part are not really deciding ethical or legal matters — they are more aptly called “prognosis committees”, and are essentially *advisory* already.
4. The court procedure is too slow and cumbersome to use for the patient’s benefit. Delays do not mean a stable condition while the court deliberates — they mean that a decision is made *to continue* treatment — often to the detriment of the patient.²³³

Let us finish this point with an appropriate comment by a physician as to the likely outcome of this decision as it affects patients. Only time will tell whether his dire prediction is accurate or not.

In some cases physicians and next of kin will probably defer urgent medical decisions, both positive and negative, pending court approval. In other cases decisions that had formerly been made expeditiously, but only after full and explicit consultation, will now be made hastily and even furtively, thus returning ‘to the closet’ questions that need open and thoughtful discussion.²³⁴

Chapter 9

Seriously Defective Newborns

The care and treatment problems and decisions involved with intensive care of newborn infants are special, and urgent. A few years ago an interdisciplinary group, some of them with direct responsibility for newborn intensive care, formulated a "Moral Policy of Neonatal Intensive Care."²³⁵

The "Moral Policy" was formulated against the background of some much discussed, but very concrete, difficult and tragic cases, such as those infants born with spina bifida and various genetic defects, as well as the still more common cases of severely asphyxiated preterm infants with respiratory distress and in need of prolonged assisted ventilation.

The group attempted to formulate a policy which could accommodate, "the diversity of private beliefs within some degree of broad agreement about how such cases should be managed" and to mingle "statements of principle with procedure". The formulators realize the policy may seem "unreal", but (rightly) argue that, "the air of unreality is, we believe, the necessary cool moment which philosophers say should precede any reasonable judgment. That judgment will have to be made amid hard realities, but it may be better made in the light of reflections on these principles."²³⁶

The ethical propositions are the following:

- (1) Every baby born possesses a *moral value* which entitles it to the medical and social care necessary to effect its well being.

- (2) Parents bear the principal *moral responsibility* for the well-being of their newborn infant.
- (3) Physicians have the *duty* to take medical measures conducive to the well-being of the baby in proportion to their fiduciary relationships to the parents.
- (4) The State has an *interest* in the proper fulfillment of responsibilities and duties regarding the well-being of the infant, as well as an interest in ensuring an equitable apportionment of limited resources among its citizens.
- (5) The responsibility of the parents, the duty of the physician, and the interests of the State are conditioned by the medico-moral principle, "do not harm, without expecting compensating benefit for the patient".
- (6) Life-preserving intervention should be understood as doing harm to an infant who *cannot survive* infancy, or will live in *intractable pain*, or cannot participate even *minimally in human experience*.
- (7) If the court is called upon to resolve disagreement between parents and physicians about medical care, prognosis about *quality of life* for the infant should weigh heavily in the decision as to whether or not to order life-saving intervention.²³⁷
- (8) If an infant is judged beyond medical intervention, and if it is judged that its continued brief life will be marked by pain or discomfort, it is permissible to hasten death by means consonant with the moral value of the infant and the duty of the physician.
- (9) In cases of limited availability of neonatal intensive care, it is ethical to terminate therapy for an infant with poor prognosis in order to provide care for an infant with a much better prognosis.

It would take us well beyond our underlying sanctity of life/quality of life concern to attempt any detailed evaluation of the many issues raised and implied in these propositions. One can at least draw attention to the way most of these propositions reflect and articulate concerns and criteria stressed earlier in the paper. They are patient centered (see especially nos. 1, 5, 6, 8); parents have the primary decision-making responsibility (see especially nos. 2, 3); quality of life considerations are central to decision-making about life saving intervention, wherever the decision is made, including in the courts (see especially nos. 6, 7, 8); central to quality of life factors are minimal human experience and intractable pain (nos. 6, 8); it is at least implied that the court is a place of last

resort, for the resolution of "disagreement between parents and physicians about medical care" (see no. 7).

As noted above, there is an occasionally disconcerting element of vagueness and openness in one or two of the formulations. But that was intentional, and is probably more of a strength than a weakness. These propositions comprise, after all, an attempt to accommodate a wide diversity of private beliefs and are not intended to be the "last word" — rather they are proposed to stimulate debate, and be only a stage towards framing questions and priorities with more precision than usual on this subject.

One proposition which is particularly vague and open, and into which one is invited to pour one's own view or opinion, is no. 8. But in my view it is just a little *too* vague to yet be useful for public policy purposes, especially in view of the very different positions the authors claim could live under its banner. As it stands, it appears to allow direct killing (euthanasia) in that, "... it is permissible to hasten death..." But the authors do not necessarily intend that meaning. "The morality of active euthanasia is far from settled. We do not intend to settle it here."²³⁸ The proposition is equally compatible, the authors maintain, with the "double effect doctrine", or the distinction between "acts of commission and omission". From the context it appears that the authors themselves might feel euthanasia is permitted, though no attempt is made to argue that view.

They do make one observation which might be intended as an argument in support of euthanasia, but is equally relevant to "allowing to die". "We suggest that there may be a significant moral difference between an infant whose therapy has been terminated and an adult whose condition is diagnosed as hopeless... For the adult, the time intervening between verdict and death may be of great personal value. For the infant, the intervening time has no discernible personal value."²³⁹ This argument in other words seems to take abilities or functions not (yet) possible for newborns (i.e. *present* self-consciousness or actual ability to reason, choose and plan) as the norm of "personal value". As such it seems very close to the kind of quality of life views this paper rejected earlier — the view which compares the worth of lives on the basis of capacities, or the one which is prepared to protect and value human life only when it achieves personhood in the "strict sense".

And yet, if we exclude any element of comparing the worth of different lives, or any suggestion that either of those two lives in

question are not valuable to *us*, then it is no doubt true that for an adult the intervening time between "verdict" and death can have *to that adult* a discernible benefit, whereas there is no *discernible* benefit in that intervening time *to that newborn*.

Chapter 10

Allocation of Scarce Resources

The problem of the allocation of scarce resources is one which will never go away, despite any utopian dreams (nightmares?) of unlimited health care for everyone, and a whole variety of efforts and proposals which more or less assume that that dream is about to become reality.

Because there are in this issue some urgent moral questions about justice and equity, as well as implications for quality of life concerns, it is one which we should look at here, if only briefly. The particular criteria we will focus on were at least an attempt (largely a failure in most peoples' view) to face the reality that we cannot have everything we want by way of medical technology and resources. They are *the admission criteria* used by the *Seattle Artificial Kidney Center* until 1972.²⁴⁰ The U.S. federal government subsequently took over financial responsibility for almost all patients needing artificial kidneys, so these criteria are in a sense history at this point. But because they did attempt to meet a real and continuing problem, and because some of the least morally justifiable aspects of those criteria continue to tempt us or to re-appear in different guises, it is never too late to look back and learn.

Of particular relevance to us here is the feature of those criteria which occasioned most of the uneasiness and opposition — namely the *social worth criteria*. There were medical criteria as well, but the *strictly* medical criteria were few — perhaps only two: a slow deterioration of renal function, and an absence of longstanding

hypertension and its permanent complications. The rest were all more or less social worth criteria such as: the patient's emotional maturity and responsibility; his demonstrated willingness to cooperate; a "physiological" age of between 17 and 50; the amount of his financial resources; his value to the community; potential for rehabilitation; psychological and psychiatric status.

The committee members were anonymous, and at one point the members were a clergyman, a housewife, a banker, a labour leader and two physicians. A physician at the Center at the time described the selection process:

There was the beatnik — in his mid-twenties, doing poorly in college (in spite of considerable effort on the part of the faculty sponsor), poor job record, and apparently without funds or plans for the future. He just did not seem to fulfill the criteria of value to the community and rehabilitation potential. There was the lady of ill repute (a veritable Camille) and although she had plenty of financial support, it was not felt that she could be considered a responsible citizen. . . A final example is the logger who seemed to qualify in every way, except that our staff and his employer simply were unable to put together any semblance of a financial package for his continued care. He expired the same day a letter of rejection and explanation went to his wife. . . ²⁴¹

No wonder then that one commentator wrote that the criteria and the selection process, ". . . paint a disturbing picture of the bourgeoisie sparing the bourgeoisie, of the Seattle Committee measuring persons in accordance with its own middle-class suburban value system: scouts, Sunday School, Red Cross. This rules out creative non-conformists, who rub the bourgeoisie the wrong way. . . The Pacific Northwest is no place for a Henry David Thoreau with bad kidneys". ²⁴²

Clearly what we have here is the use and abuse of "quality of life" considerations, but quality of life understood in the sense this paper has consistently rejected as immoral in this context — that of relative social worth, or social value, involving a determination by others of the "worth" or "value" of people according to extrinsic, subjective and relative criteria.

One commentator has well identified the immorality of "social worth" selection criteria: ". . . we have *no way of knowing how* really and truly to estimate a man's societal worth or his worth to others or to himself. . . The *equal* right of every human being to live ought generally to prevail. . . [emphasis added]." ²⁴³ He goes on to write, "No one can tell the worth of an old man sitting on the porch watching a sunset, or ponder imponderables like the relative moral

worth of comparative genetic inheritances, or say whether a disturbed or seemingly undisturbed child should be saved. When tragically not all can be saved, the rule of practice must be the *equality* of one life with every other life. . . .²⁴⁴

How then ought we to make choices in such matters? What is the best method? The first answer is that we will never know for sure. But that does not mean we are wrong to reject "social worth". In the words of L. Fuller, "We can . . . know what is plainly unjust without committing ourselves to declare with finality what perfect justice would be like."²⁴⁵

Generally speaking there are four methods proposed for the selection of patients for access to scarce resources: (1) social worth; (2) selection rules based on statistical medical probabilities (*i.e.* "all persons over 40 will be excluded from hemodialysis"); (3) random selection by lottery or on the basis of "first come, first served"; (4) when not all can be saved, no one should be selected.²⁴⁶

As Paul Ramsey notes, there are essentially only two principles to choose between — randomness among lives presumed to be equal, and comparison of social worthiness. Only the former, ". . . would ensure equality of opportunity to live, and not die, to every one of a class of patients, and it would forbid the physician from raising questions of comparative social merit as a means of determining who lives and who dies".²⁴⁷

But of course none of these considerations, important as they are, have yet come to grips with (what should be but seldom is) our prior and more fundamental concern, namely the establishing in a rational manner, of social and medical priorities and needs. Questions about who should have access to scarce *existing* resources, surely should come second in time and importance to questions about how we establish our priorities about the kinds of medical technology and services we will make available, and which resources *shall be* plentiful and which scarce. As long as there will be limits to what can be provided (presumably forever), and other claims and needs competing with the medical ones, the need to establish priorities will exist. It is of course essential to establish (as we have tried to do above) the principle that everyone should have an equal opportunity of access to the existing medical resources, plans and services, but what shall they be?

It is a common and generally justified complaint that health care discussions and questions are too seldom fundamental enough, too

seldom aware of the larger and ultimately more influential (for good or ill) contexts, issues and dilemmas. Consider for example this "minority view" by one of the participants at a conference discussing newborn intensive care:

We cannot dismiss the economics of neonatal intensive care by simply stating, 'an infant is not simply a commodity whose value is defined by its utility.' Questions should be raised: Who benefits economically from neonatal intensive care? . . . Furthermore, what are the preventative possibilities, and why was this not relevant? Can the number of such (deformed) infants be reduced by monitoring drug, geneology, and environmental inputs? . . . We never pursued the question, how has our society come to be spending so much time and money on neonatal intensive care without similar attention to born healthy, but later not so healthy, deprived children — is this development related to special interests that may be ours although we are unaware of them?²⁴⁸

It has been suggested that as long as medical needs will exceed our resources, some form of "triage" might be a just social policy.

. . . We may have to learn not always to give the advantage to spectacular and costly treatments in ordering our priorities, if medical resources are ever to be distributed justly. This would be a form of triage, accepting the death of some of the most desperate sorts of cases in order to give the first attention to many whose needs are urgent, to be sure, but who are not yet at the end stage of some fatal illness. . . when not everything can be done that ideally should be done, it does not necessarily follow that the maximum research and personally and socially worthy medical care should be expended upon the most desperate cases first.²⁴⁹

Aspects of such a policy are well worth considering. But there are as well some serious problems and dangers with a policy of ordering our medical resource priorities according to a triage approach. Triage as a general policy could well turn out to be a "social worth" criterion in another guise. Two dangers in particular merit consideration. "First, common good considerations are, in practice, often, disguised special interest considerations. Favoured treatment of certain persons or classes is judged, by those identified with those persons or classes, to contribute to the common good. Secondly, the hope of survival with maximal function is predicated not only on the physical potential of the infant but on the socioeconomic world into which it enters. Thus, estimates of the quality of future care may bias selection."²⁵⁰

But not only do we need to establish medical priorities *within* the medical field — those priorities must themselves be weighed by the *larger context of social priorities*. "To what extent ought medical needs be served in comparison to eradicating poverty,

stopping the decay of our cities, depolluting our atmosphere and streams, defending the nation, and aiding underdeveloped peoples? Again, it is quite clear that while all things are possible, all things are not compossible, as Leibnitz said."²⁵¹

A major temptation to be resisted is that of making the *cost* factor the only effective and articulate criterion in establishing these priorities. If cost factors are the major or only considerations, then decisions about medical priorities tend to be ad hoc, irrational and inadequate. Just because there is X amount of money left in the hospital or Health Ministry budget is not in itself enough reason to buy this piece of medical equipment rather than that one, or to start this program as opposed to that one.

The (moral) questions are for instance: where are the *greatest needs* (and not just the loudest voices); what *norms* are the most justifiable for determining those needs and establishing priorities; *who will be served* by each option, what are the *rejected* options implied in each positive choice, and what needs or segments of society will be *less served* because of any particular choice of a service, a program or a technology; do we value and respect lives sufficiently to (sometimes drastically) *re-allocate* our (budget) priorities in order to provide humane care; should the value of life be reduced largely to *cost-benefit* analysis (too often with more emphasis on cost than on benefit).²⁵²

Whether or not we need more legislation directly addressing the issues of methods and priorities in the allocation of and access to health resources is difficult to say. But there is at least an urgent need for hospital administrators and Health Ministries to articulate and publicize the norms they use at present. Only if this is done can citizens be reassured that there are in fact such norms being used.²⁵³ Only if this is done can we be reassured that "social worth" criteria have not crept in and quietly become normative in one guise or other. Only if this is done as a first step can there be a healthy public debate. If such a disclosure and debate takes place, "... it could happen we the people might learn not only the direction in which to throw tax money for medical research and the distribution of medical services, but also how as a people we should go about deciding the nation's priorities in general."²⁵⁴

Chapter 11

Natural Death/Living Will Legislation

As argued earlier, from the ethical perspective the decisive factor in treatment decisions normally ought to be patient wishes, based upon the patient's right to self-determination. This self-determination extends to determining one's own quality of life in terms of one's own mix of values such as ability to function and degree of pain, and accordingly at some point deciding to refuse treatment and be allowed to die.

But what if the patient is no longer competent, is comatose for instance? In such instances the first concern of the physician would normally be whether or not the patient orally or in writing indicated whether or not he or she wished treatment to be initiated, continued or discontinued in the event of a particular medical diagnosis and prognosis. Some sort of informal, previously written indication (in recent times often called a "living will") can be very helpful and reassuring to both patients and physicians, and an important protection and extension of patient wishes and self-determination when and if the patient is no longer able to communicate.

In my view one of the best expressions to date of such a "living will", one which incorporates many of the concerns we have considered in this paper, is that proposed by Sissela Bok:

I wish to live a full and long life, but not at all costs. If my death is near and cannot be avoided, and if I have lost the ability to interrelate with others and have no reasonable chance of regaining this ability, or if my suffering is intense and irreversible, I do not want to have my life

prolonged. I would then ask not to be subjected to surgery or resuscitation. Nor, would I then wish to have life support from mechanical ventilators, intensive care services, or other life-prolonging procedures, including the administration of antibiotics and blood products. I would wish, rather, to have care which gives comfort and support, which facilitates my interaction with others to the extent that this is possible, and which brings peace.²⁵⁵

But ought these "living wills" to be supported *in law*? Would patient wishes, patient self-determination be given still greater protection and scope if living wills were made legal documents, supported by "natural death" legislation? In my view both the arguments supporting that move and the examples of natural death legislation and legal living wills enacted or proposed to date, suggest that patient self-determination might more likely be eroded than reinforced.

That the translation of living wills into legislation has caught on in recent years is evident. In the U.S. the trend began with the introduction of a Natural Death Act in Wisconsin in 1971. In one year alone (1976), 17 States had variations of Natural Death/Living Will Bills under consideration. In 1976 California became the first State to actually pass legislation.²⁵⁶ In 1977, 7 States enacted Natural Death Acts, most of them using the California model with some variations. So far the only Canadian legislative proposal was a Bill entitled the *Natural Death Act* introduced as a Private Member's Bill in the Ontario Legislature in 1977. It too was loosely based on the California Act. It was given second reading, but in the face of considerable opposition from various groups as well as new reservations on the part of the Member who introduced it, it was not reintroduced after a government election.

It cannot be my purpose here to attempt a detailed description or evaluation of these Bills. It is enough to note that the features common to most of these Bills, at least the more recent ones are these:

- (1) The Bills recognize the right of adults to direct physicians to withdraw "extraordinary" life sustaining treatment in specified circumstances of terminal illness.

- (2) Terminal illness is defined as one which will result in "natural death", whether life sustaining procedures are used or not.

- (3) One becomes a patient "qualified" to so instruct one's physician once one has been diagnosed as terminal, and verified

as such by one or more physicians. There is generally a "cooling off" period specified between the diagnosis and the (valid) signing of a directive (two weeks, in California).

(4) The physician who complies, as well as the health facility, are protected from liability.

(5) In most cases, no real penalty is attached for violation.

My primary reservation about living will legislation of this kind is a general and basic one. It is one well expressed in these words:

The very fact that a law is deemed necessary to assure patients' rights implies, and therefore tends to reinforce, an erroneous presupposition about the locus of decision-making in the physician/patient relationship.²⁵⁷

Two points already noted or argued earlier are relevant to this issue. First of all, patients already have the right to refuse medical advice and treatment, whatever the physician might think of that refusal. Secondly, if the patient is comatose or otherwise incompetent, parents or family (not physicians or courts) in the first instance, have the responsibility and right to make decisions involving cessation of treatment. That means if a physician does not agree with a family's request about its patient-relative, the physician, not the family, should appeal to the courts.²⁵⁸

There are a number of reasons why laws about natural death and living wills are likely to encourage a shift in decision-making laws away from patient/family towards the physician, and to make the physician more a servant of the statute than of the patient.

The major reason is this: in defining terminal illness in a very narrow way, and in securing rights for the very small range of cases which fit the specifications of those qualified to write legally valid instructions, a "natural" right to refuse treatment in *many* situations is by implication reduced to a conferred or acquired right in this one situation. The securing of rights for *some*, risks the curtailing of rights for a much larger number. The danger is that physicians will assume that those who could have signed a directive but did not (likely the vast majority), wish vigorous and "useless" (extraordinary) treatment to continue. Insofar as this danger is real, the onus will have shifted to the patient to write such a formal directive, and away from the traditional recognition of patient wishes communicated in a less formal (even oral) manner, away from the traditional recognition of allowing patients to die for a wide range of reasons,

away from the traditional recognition of a right to refuse treatment which puts the onus of legal recourse on physicians and others who disagree, not on the patient.

The *California Natural Death Act* (Assembly Bill 3060) is a case in point. It states that only mechanical or other artificial means to restore or supplant a vital function may be withheld or withdrawn, and only when death is imminent whether or not life-sustaining procedures are used. As a result many situations in which treatment refusal is normally acceptable are excluded. For instance, "... the directive only takes effect when 'my death is imminent'. Thus many patients would not be permitted to have treatment stopped (by signing the directive) at a time when they are declining and treatment has become burdensome, useless, or both, but when death is still not imminent."²⁵⁹

In effect then the most serious danger of these Bills is that the patient-centered perspective may be given less, rather than more, protection and scope. As one comment on the California Bill put it, "The right to withhold or withdraw useless treatment applies to 'natural' as well as 'artificial' means, and to situations where the patient has not signed a 'directive' and is not competent. . . Physicians welcome AB 3060 because it exculpates them in specified circumstances. But if the signing of this Bill would make them hesitant to follow their religious and moral traditions in circumstances not covered by AB 3060, then patients' rights will be abrogated and it will in fact become *harder* to die."²⁶⁰

It is sometimes argued that natural death/living will legislation is primarily necessary because otherwise physicians will continue to treat the terminally ill too vigorously, despite patient wishes. Three points can be made against this argument.

First of all it is true that some studies indicate that patients who are seriously or terminally ill do have difficulty communicating their wishes to their physicians.²⁶¹ But while this may well be an argument for written living wills, it is not necessarily one for "legislated" living wills.

Secondly, some surveys indicate that the cases in which physicians are likeliest to actively treat against the wishes of patients or patient agents are not those in which death is imminent, but those in which the patient can be maintained for a considerable period of time.²⁶² But such patients are not even "qualified" to write directives according to most living will legislation. As for the

imminently terminally ill, some surveys suggest most physicians do respect patient wishes about the nature and extent of care.²⁶³

Thirdly, these surveys do suggest that a majority of physicians, when they do not accede to patient wishes, hesitate because they fear that to accede might constitute malpractice or even make them liable to homicide charges.²⁶⁴ But this is not necessarily an argument for legislated living wills. It may be a better argument for alternative legislation.²⁶⁵ For instance it may be more direct and to the point to design relevant legislation to clarify more fully the physician's liability in such cases, (if that is the real problem), than to design legislation which pretends that the problem is protecting patients from over-treatment by physicians, and in the process risks increasing precisely that danger.

However, to argue for legislation which at least in general terms clarifies the physician's liability in these and other cases, is not to argue for a form of "no risk", "no fault" decision making for physicians by providing some form of legal immunity for all cases in which physicians cease treatment for terminally ill incompetent patients. A degree of risk and personal responsibility in such decision making will and should remain, and it would undoubtedly be a form of irresponsibility for physicians to wish to defer or escape making decisions and taking action until and unless they are provided with guaranteed legal immunity, or absolute prior certainty in every case as to their legal liability.

After all, no other profession regularly exposed to decision making in which the death of others is an ever present possible result (soldiers, police, airline pilots, etc.) is granted that kind of immunity. It is worth recalling that, "Because these decisions, dispensing life and by necessary implication dispensing death, press upon our most basic communal identities, I think it proper that society impose an extraordinary burden of care-taking on these physicians. The possibility of criminal liability should force these physicians to give of themselves, to identify both with the family and with the newborn child as if the suffering were the physician's own. . . ." ²⁶⁶

PART IV

CONCLUSIONS: SOME PRIORITIES FOR PUBLIC POLICY AND LAW

Preamble

(1) On the one hand law is entitled to address itself to the issues dealt with in this paper. There are important individual and societal values to be underlined, rights and duties to be protected, public debate to be invited and formal decision-making and conflict-resolution processes to be used and evolved. All of these, in part at least, are the proper tasks of the legislative forum (Parliament and Provincial Assemblies) and of legal justice (laws and courts). The former to focus public debate and formulate public policy, the latter to dramatize and articulate the ideals of legal justice — impartiality, objectivity, consistency, fairness and equality.

(2) But on the other hand (as noted in the Introduction), the mere presence of endangered values and rights or of immorality does not necessarily mean in every instance that law should be brought more directly and frequently into play. In some instances it may be too blunt, too insensitive to better the situation. More law and legal process may in some instances only further bureaucratize and depersonalize a medical system which, by general consensus, has already gone too far in that direction.

Wherever possible there should be room for both an ethic of rights and an ethic of responsibility in any law reform proposal. The general maxim that law should play a limited, "last resort" role is applicable to our issues. In many instances there may be people,

processes and socializing agencies at more fundamental, more immediate levels better able to encourage responsibility and protect the rights in question. About any particular medically oriented issue there is therefore some onus on legislators and law reformers to establish not only that this or that particular law is better than another, but that law itself belongs here, is likely to do a better job than another and perhaps less intrusive means or at least likely to play a useful supplementary role.

(3) When it comes to the formulation or re-formulation of particular public policies, laws or law reforms in this area, an essential and primary consideration is the determination of just where the real problem is, which particular issue should be regulated or legislated to best cope with a perceived problem and endangered rights, and which issues if directly regulated or legislated in might actually finish by only further depriving these or other patients of the very rights one seeks to better protect.

(4) Legislation or any other form of social policy enacted or reformed in any of the areas discussed in this paper, should not seek to provide for physicians a form of "no fault" immunity from prosecution or civil suits. Even if such legislation were feasible, it would not likely promote the high standard of care encouraged by continuing to allow all such medical decision-making to be reviewable by courts, and by continuing to allow physicians (and others involved in these decisions) to be responsible for their decisions and actions. Rather than seeking full legal immunity, physicians should continue to accept the responsibility of sometimes allowing a patient to die by ceasing or not beginning useless or burdensome-to-patient treatment, and at other times accept the responsibility of not neglecting patients who are treatable and able to be cared for, even though their quality of life is minimal. In any clarification of responsibility and liability in these matters, it should be stated or assumed that the sanctity of life principle imposes a greater burden of proof on those who would allow to die than on those who would continue to treat.

(5) In view of the fact that this paper was not intended to be an in-depth analysis and evaluation of existing law, the specifics which follow are not necessarily meant to be proposals for law reform. In some instances at least, the law may already adequately reflect the (moral) concerns expressed in these specifics. That is for others to

determine. They are offered only as a summary and selection of some of the moral considerations dealt with in this paper, those which ought to be central concerns in public policy, law and law reform as regards the protection of both the sanctity of life and the quality of life.

Specifics*

(1) Public policy and law should (continue to) affirm and protect the absolute value, equality and "sanctity" of human life, and continue to prohibit (active) euthanasia for any reasons. But at the same time, it should make explicit that what it is affirming and protecting is the absolute value of human *personal* life, of persons.

(2) Public policy and law should acknowledge that sometimes death of the person may and will have to be established by a quality of life criterion, namely that of irreversible brain death (either of the whole brain or of the cerebral centres). And this even though human biological life in the form of circulatory and respiratory function continue, either spontaneously (in the case of cerebral death only) or artificially (in the case of whole brain death). It should be explicitly affirmed that physicians have no legal liability for not initiating or for ceasing "life" saving or "life" supporting treatment in such cases of biological human life alone, assuming of course that all the necessary tests have been carefully made.

(3) Public policy and law should acknowledge that even in the presence of human personal life there can exist good quality of life reasons for not initiating or for ceasing medical treatment. Applied to both competent and incompetent patients the determinative criterion is the *patient's perspective*, the patient's benefit. In the case of competent patients, they should be free to interpret and determine what is to their benefit by themselves, refusing treatment on any grounds they wish. Decisions by others for incompetent or incoherent patients should be made according to the "reasonable person" test, determining both whether the treatment is *useful* and whether it would occasion *serious patient-centered objections* or burdens. Physicians who cease or do not initiate life saving or life supporting treatment either because the treatment is not useful, or

* For more detailed conclusions see the concluding sections of chapters 1-6.

would occasion a serious patient-centered objection, or both, should not incur legal liability.

(4) But if quality of life criteria are to be given any normative value in public policy and law for purposes of determining whether a particular medical treatment is (or was) useful as well as not excessively burdensome to the patient, then two serious dangers must be protected against. It is by no means certain that adequate protection can in fact be included in such laws and public policies.

The first danger would be to leave the term "quality of life" too vague and general, simply allowing "reasonable medical judgment" to determine the meaning and normative weight to be given to quality of life factors in given cases. Unless relevant public policy and law can articulate and defend some *substantive* quality of life criteria, the mere recognition of such criteria in general without any further specificity would probably be at best unhelpful, and at worst dangerously vague.

In other though related matters laws have usually been formulated in somewhat general terms, leaving it to the particular profession to determine and add the specifics to general (legal) standards such as "reasonable care and skill". But in the matter of quality of life standards in the medical context, this (traditional) manner of formulating relevant law would probably be inadequate. "Quality of life" as a norm for life and death medical decision-making is too elastic a term, and too much in need of public review and control to be "legalized" without carefully drawn definitions and parameters. Whether laws *can* in fact be moved in this direction in this matter is for others to decide.

The second danger in such a recognition would be to articulate quality of life criteria which have not been purged of any connotation of social utility, relative worth or merely subjective considerations. Such criteria would expose incompetent and non-competent patients to more risks than benefits. Therefore the criteria should not only be substantive, but as objective and patient-oriented as possible.

The two criteria suggested in this paper merit consideration. The first considers the patient's capacity to experience and relate. The second considers the intensity and the susceptibility to control of the patient's pain and suffering. If, even with treatment and loving care, a reliable diagnosis and prognosis indicates that there is not now and

apparently never will be even a minimal potential capacity to experience and relate, or that the level of pain and suffering will be prolonged, excruciating and intractable, then and only then would a decision to cease or not initiate life supporting or life saving treatment for an incompetent or non-competent patient be beneficial and acceptable.

(5) It should be clear and explicit in public policy and law that all patients have the right to refuse treatment by withholding consent, even if death will inevitably result. This applies to both competent and incompetent patients. The competent should make such decisions for themselves, and for the incompetent or incoherent, a previously chosen agent, family member, or court appointed guardian (and in that order of authority) would exercise that right for them. The mere refusal of a "dying-prolonging" treatment by a competent patient should not be used as grounds for declaring a person incompetent.

(6) In the case of presently incompetent or incoherent (but formerly competent and coherent) patients, it should be clearly recognized in public policy and law that their wishes regarding initiation, continuation or cessation of treatment which were clearly and knowledgeably expressed when competent and coherent, are to be now respected.

(7) Since, as this paper has argued, medical (curative) *treatment* may be stopped under certain circumstances, though *care* or comfort continue to be morally obligatory, the law should recognize and define as clearly as possible the distinction between what I have called "(curative) treatment" and "(palliative) care". Clarity in this regard would make it possible to establish with (more) accuracy in what sorts of circumstances it is the physician's duty to treat as well as care, and when no such duty to treat exists, but only one of caring.

(8) Knowledgeable and informed medical decisions by patients or proxies to initiate, continue or cease treatment on the basis of quality of life considerations are impossible without full information and understanding as to the diagnosis, prognosis, risks and benefits involved. Such information and understanding is obviously all the more crucial in decisions involving life supporting or life saving

treatment. Therefore any relevant public policies and legislation concerning medical decision-making of this nature should be clear and unambiguous as to the patient's right not only to withhold consent, but also to be fully and clearly informed, and the physician's duty to so inform. When necessary of course, both the patient's right to be fully informed and the patient's right to withhold consent, will be exercised by a proxy (or proxies) for that patient.

Endnotes

1. For a helpful discussion along these lines see Steve Wexler, "The Interaction of Law and Morals", *The Canadian Bar Review*, 54, 2, June '76, pp. 351-359.
2. One of the best recent treatments of the mutual interaction of law and religion from both historical and contemporary perspectives, is that of the Harvard Law Professor, Harold J. Berman, in *The Interaction of Law and Religion*, Abingdon Press, N.Y. 1974. See also Basil Mitchell, *Law Morality and Religion in a Secular Society*, Oxford U. Press, London, 1970.
3. It would not be accurate to suggest that there is *always* a gap between legal theory and practice in these cases. For instance, the law tends to be very skeptical both in theory and practice about medicine's ability to predict imminent death, or the likely level and extent of recovery if treatment is continued or initiated. Courts tend to put a very high value on even slight chances of survival. A number of recent court cases in the U.S. suggest that the present legal duty of intensive care unit staff for instance is to continue their efforts on behalf of the patient as long as there is any measurable chance of survival, even as little as one or two percent. See George T. Annas, "Decision Making and the Critically Ill Patient: Some legal Aspects of a Patient Classification Scheme", *Linacre Quarterly*, 42, 2, May '75, 116-122.
4. While no case clearly involving euthanasia has yet been decided by a Canadian court, there have been cases in the U.S. and Britain, both of which have much the same legal principles and laws as Canada. Presumably Canadian decisions would be similar in "euthanasia" type cases. Regarding the defence of insanity, see Sanders, Joseph, "Euthanasia—None Dare Call it Murder", *Journal of Criminal Law Criminology and Police Science* No. 3, 1969, 351-359.
5. Becker, Ernest, *The Denial of Death*, Macmillan, N.Y., 1973.
6. Choron, Jacques, *Death and Western Thought*, Collier, N.Y., 1963.
7. Ariès, Philippe, *Western Attitudes Toward Death, from the Middle Ages to the Present*, Johns Hopkins U. Press, Baltimore, 1974.

8. Illich, Ivan, *Medical Nemesis*, McClelland and Stewart, Toronto, 1975.
9. Callahan, Daniel, "The Sanctity of Life", in Donald R. Cutler (ed.), *Updating Life and Death*, Beacon Press, Boston, 1968, p. 185. For much of what follows on the sanctity of life I am indebted to this analysis by Callahan.
10. Kohl, Marvin, *The Morality of Killing*, Humanities Press, Atlantic Highlands, N.J., 1974, p. 3.
11. Williams, Granville, *The Sanctity of Life and the Criminal Law*, Faber and Faber Ltd., London, 1958.
12. See Harold J. Berman, *The Interaction of Law and Religion*, op. cit., note 2, pp. 49-76. See also, Julius Stone, *Human Law and Human Justice*, Stanford U. Press, Stanford, California, 1968, especially pp. 9-35.
13. Barth, Karl, *Church Dogmatics*, Vol. 3, Part 4, T. & T. Clark, Edinburgh, 1961, p. 339.
14. Ramsey, Paul, "The Morality of Abortion", in John Rachels (ed.), *Moral Problems: A Collection of Philosophical Essays*, Harper & Row, N.Y. 1971, pp. 11-12.
15. St. John-Stevas, Norman, *The Right to Life*, Holt, Rinehart and Winston, New York, 1964, p. 12.
16. Ramsey, Paul, op. cit., (note 14) p. 13.
17. Callahan, Daniel, op. cit., (note 9) p. 190.
18. In the final analysis the latter part of this statement is not very helpful as it stands. The expressions, "human nature" and "radical change" are vague and general without further specification. What exactly is "human nature"? What specific changes would be "radical"? Later in the paper (especially in the "person as a normative concept" section) I will attempt to deal in some detail with the first question, at least as it relates to issues of death and dying. As for the second question, it is of course largely dependent on the first. One can only begin to know what changes and what acts (medical or experimental or behaviour modifying) come under the heading of "radical" once one has opted for a particular view of the distinctively and normatively human. But since even "radical" change admits of levels and degrees, debate will (and should) continue, even among those who agree generally on the normatively human characteristics, as to whether the change resulting from a particular medical act is radical or minor.
19. This latter point is made emphatically by St. John-Stevas, who writes, "This respect for human life has become part of the moral consensus of Western society. It has got there, as Sir Patrick Devlin says of the permanent marriage contract, 'because it is Christian, but it remains there because it is built into the house in which we live and it could not be

removed without bringing it down' . . . Once the principle of the sanctity of life is abandoned, there can be no criterion of the right to life, save that of personal taste." St. John-Stevas, op. cit., (note 15) pp. 12, 17.

20. Gustafson, James M., "The Contributions of Theology to Medical Ethics", *Perspectives in Biology and Medicine*, Winter '76, p. 270.
21. Shils, Edward, "The Sanctity of Life", in Daniel H. Labby (ed.) *Life or Death: Ethics and Options*, U. of Wash. Press, Seattle, 1968, pp. 2-38.
22. Ibid, p. 9.

Shils in fact goes further and argues that "The transcendent sacred is a construction which the human mind itself has created to account for and to place in a necessary order the primordial experience and vicissitudes of the actual embodiment of vitality to which it attributes sacredness" (p.13). "If man did not prize his own vitality, the sacred and its vast symbolic elaboration into cosmogonies and theologies would not exist" (p. 14).
23. Ibid. pp. 12-13.
24. Medawar, P. D., "Genetic Options: An Examination of Current Fallacies", in Daniel H. Labby (ed.), *Life and Death: Ethics and Options*, U. of Wash. Press, Seattle, 1968, p. 78.
25. Barth, K., op. cit., (note 13) p. 339.
26. Shils, E., op. cit., (note 21) p. 15.
27. Clouser, K. Danner, "The Sanctity of Life: An Analysis of a Concept", *Annals of Internal Medicine* 78: 119-125, 1973, pp. 120, 121.
28. Shils, E., op. cit., p. 19.
29. Kluge, Eike-Henner W., *The Practice of Death*, New Haven and London, Yale University Press, 1975, p. 142.
30. Pendengast, Richard J., Letter, *Annals of Internal Medicine* 78, 6, June, 1973, p. 979.
31. Winget, C., Kapp, Frederic T., Yeaworth, Rosalee C., "Attitudes Towards Euthanasia", *Journal of Medical Ethics*, 3, 1977, p. 20.
32. Tendler, Dr. Moshe, as cited by Howard Brody in *Ethical Discussions in Medicine*, Little, Brown and Co., Boston, 1976, p. 66.

A similar Jewish view is expressed by Byron Sherwin, "According to Jewish law, life is to be preserved, even at great cost. Each moment of human life is considered intrinsically sacred. Preserving life supersedes living the 'good life'. The sacredness of life and the uniqueness of the individual require that every possible action be taken to preserve life." "Jewish Views of Euthanasia", in Marvin Kohl (ed.), *Beneficent Euthanasia*, Prometheus Books, N.Y., 1975, p. 7.

33. Rostand, Jean, *Humanly Possible: A Biologist's Notes on the Future of Mankind*. Saturday Review Press, N.Y. 1973.
34. DeMarco, Donald, *Catholic Register*, Jan. 23, 1978.
35. Carter, Bishop E., as cited by Wilfred Murphy in the *Elmira Ontario Independent*, Nov. 30, 1977.
36. Rostand, Jean, op. cit. (note 33).
37. I say "may" because as a historical fact there is some uncertainty as to what the original intentions of the Nazi program were. Some maintain that racism—purification of the Aryan stock—was in fact the original intention. It is probably not a coincidence that those of this view tend to be in favour of (direct) euthanasia and argue from this (against the wedge argument) that the Nazi experience does not provide a good (wedge) argument against euthanasia, as that program was compromised from the beginning. Indiscriminate euthanasia (they argue) is therefore likely only in a Nazi like society. See for instance Marvin Kohl, "Voluntary Beneficent Euthanasia", in Marvin Kohl (ed.) *Beneficent Euthanasia*, Prometheus Books, Buffalo, N.Y. 1975, p. 137. But for another view see Leo, Alexander, "Medical Science under Dictatorship", *New England Journal of Medicine*, 241 (1949) pp. 39-47, and Davidowicz, Lucy C., *The War Against the Jews, 1933-1945*, Holt, Rinehart and Winston, N.Y. 1975, pp. 131-34. There is some evidence suggesting that a euthanasia policy for largely utilitarian and racist reasons might in fact be acceptable even in our contemporary society. See Mansson, Helge Hilding. "Justifying the Final Solution", *Omega*, 3, (1972) pp. 79-87.
38. Bettelheim, Bruno, *The Informed Heart*, London, 1961.
39. Kluge, Eike-Henner W., op. cit., (note 29) p. 137.
40. Gustafson, James N., "Basic Ethical Issues in the Biomedical Fields", *Soundings*, 53, Summer 1970, p. 164.
41. Kaplan, Abraham, "Social Ethics and the Sanctity of Life: A Summary", in Daniel H. Labby (ed.), *Life or Death: Ethics and Options*, U. of Wash. Press, Seattle, 1968, pp. 154-155.
42. Editorial, *The Globe and Mail* (Toronto), April 13, 1978, p. 6.
43. Fletcher, Joseph, "The Right to Live and the Right to Die", *The Humanist* 34, 4, July-August, 1974, p. 12.
44. Ibid., p. 13.
45. Ibid., p. 13.
46. Clouser, K. Danner, op. cit., (note 27) p. 121.
47. Ibid., p. 122.
48. Ibid., p. 122-123.

49. Kohl, Martin, *The Morality of Killing*, op. cit., (note 10) p. 30.
50. Ibid., p. 95.
51. The leading theologians of these "schools" are both Protestant and Catholic, and include: Dietrich Bonhoeffer, Karl Rahner, Johannes Metz, Harvey Cox, Rudolf Bultmann, W. Pannenberg, Gustave Thils, Friedrich Gogarten, Teilhard de Chardin and many others.
52. Bonhoeffer, Dietrich, *Letters and Papers from Prison*, Macmillan, N.Y., 1962, p. 196.
53. Pastoral Constitution, *Gaudium et Spes*, on the Church in the Modern World, in *The Documents of Vatican II*, Walter M. Abbot (ed.), London, 1966, no. 36.
54. Metz, Johannes, *Theology of the World*, The Seabury Press, N.Y., 1973, p. 57.
55. Ibid., p. 59.
56. Ibid., p. 57.
57. Ibid., p. 58.
58. Ibid., p. 64.
59. Ibid., p. 67.
60. Ibid., p. 74.
61. Rahner, Karl, "Experiment Man", in *Theology Digest*, Sesquicentennial Issue, Feb. 1968, p. 61.
62. Guttmacher, Alan F., "The United States Medical Profession and Family Planning", in Bernard Berelson (ed.), *Family Planning and Population Programs*, U. of Chicago Press, Chicago, 1966, p. 458, as cited by D. Callahan, "The Sanctity of Life", op. cit., p. 216.
63. Gustafson, James, "Basic Ethical Issues in the Biomedical Fields", op. cit., (note 40) p. 164.
64. Aiken, Henry David, *Reason and Conduct*, Alfred A. Knopf, N.Y. 1962. See especially ch. 4, "Levels of Moral Discourse". I am equally indebted to Daniel Callahan for suggesting the application of Aiken's view to the sanctity of life principle in particular (see his, "The Sanctity of Life", op. cit., note 9, pp. 196-202).
65. Ibid., p. 71.
66. Ibid., p. 75.
67. Gustafson, James, "Basic Ethical Issues in the Biomedical Fields", op. cit., (note 40) p. 152.

68. Aiken, Henry David, op. cit., (note 64) p. 76.
69. Ibid., p. 77. To "go beyond ethics altogether" would take us to what Aiken calls the "post-ethical" level—see Aiken p. 83 ff. It would take us too far afield to include a discussion here, especially since that would get us into a major issue in ethics, namely, "Why should one be moral?"
70. Ibid., p. 80.
71. Ibid., p. 82.
72. Ibid., p. 82.
73. Callahan, D., "The Sanctity of Life", op. cit., note 9, p. 198.
74. For one of the more detailed and perceptive treatments of moral rules, see Gert, Bernard, *The Moral Rules*, Harper & Row, N.Y., 1970.
75. This list of rule systems and much of what follows is from D. Callahan, "The Sanctity of Life", op. cit., (note 9) p. 201 ff.
76. Ibid., p. 208.
77. This point has been well made by Abraham Edel. "The domain of ignorance is and will be indefinitely vast. But from a practical point of view, it can no longer be used as an *a priori* veto on attempts at knowledge and control. In more stable days, it could be said that no experimental ventures should be made in human life which involved a plunge into the unknown, because disasters might result. Now the same argument can be urged against *not* making experimental ventures; for the consequences of continuing in the old ways in a rapidly changing world may be quite as unknowable and quite as disastrous. This argument does not justify recklessness in experiment; we are learning how reckless we have been. But it underlines the recklessness of conservatism too. In short the emphasis falls on responsible attempts at control." "Scientists, Partisans and Social Control", *Transaction*, Jan. 1972, p. 34.
78. Editorial, *California Medicine*, Sept. 1970, pp. 67-68.
79. Weber, Leonard J., *Who Shall Live?* Paulist Press, N.Y., 1976, pp. 41-42.
80. *The Quality of Life Concept*, U.S. Environment Protection Agency, Washington, D.C., 1973, p. iii.
81. Baier, Kurt, "Towards a Definition of Quality of Life", in Peter C. List and Ronald O. Clarke (editors), *Environmental Spectrum*, D. van Nostrand Co., N.Y., 1974, p. 67.
82. See for instance, U.S. Environmental Protection Agency, *Quality of Life Indicators*, 1972. Also, Dillman, Don A., and Tremblay, Kenneth R., "The Quality of Life in Rural America", *The Annals of the American Academy of Political and Social Science*. 429, Jan. '77, 115-129.

83. See for instance, Office of Management and Budget (U.S.), *Social Indicators*, Washington, 1973, p. xiii, also, *Perspective Canada*, Ottawa, 1974, p. xxii.
84. McCall, Sorrs, "Human Needs and the Quality of Life", in John King-Farlow and William R. Shea (editors), *Values and the Quality of Life*, Canadian Contemporary Philosophy Series, Science History Publications, N.Y., 1976, p. 14.
85. Ibid., p. 15.
86. Ibid., p. 18.
87. Maslow, Abraham, *Motivation and Personality*, N.Y., 1954, pp. 35-47, as cited by McCall, op. cit., p. 19.
88. This is a suggestion convincingly argued by Storrs McCall, op. cit., note 84, pp. 20-21.
89. Baier, Kurt, "The Sanctity of Life", *Journal of Social Philosophy* 5, (2), April '74, p. 5.
90. For probably the best treatment of the obligation and significance of "Care", see Paul Ramsey, "On (Only) Caring for the Dying", ch. 3 of his *The Patient as Person*, Yale University Press, New Haven, 1970, pp. 113-164.
91. Kautzky, R. "Der Arzt", *Arzt und Christ* 15 (1969), 138, (as cited by R. McCormick, "The Quality of Life, The Sanctity of Life", *Hastings Center Report*, 8, 1, Feb. '78, p. 34).
92. One can think of no compelling moral or medical reason why, once death has been declared, such "unburied corpses" cannot continue to be maintained biologically alive for any length of time as "vital organ banks" or "tissue banks". As one moralist puts it, "it seems to me that one should not speak in such cases of having maintained 'life'. For what is really maintained is merely certain limited biological functions. To put it more pointedly, there has been a preservation of the vitality of specific organs of an unburied corpse . . . the organism as a whole has ceased to be . . ." Thielicke, Helmuth, in Kenneth Vaux (ed.) *Who Shall Live? Medicine, Technology, Ethics*, Fortress Press, Philadelphia, 1970, p. 176.
93. Capron, A. M. and Kass, L. R., "A Statutory Definition of the Standards for Determining Human Death: an Appraisal and a Proposal", *U. of Penn. Law Review*, 121, Nov. 1972, p. 111.
94. The major such test would be the presence of a flat EEG (Electroencephalogram). Because some brain activity can apparently still remain even if the EEG indicates no electrical activity, it can be only of confirmatory value for the determination of *whole brain* death. But because it measures mainly neocortical or higher brain activity, it can be the central and major test for *cerebral* death. Its reliability for that purpose has been

strongly supported by medical evidence. See D. Silverman *et al.*, "Irreversible Coma Associated with Electroencephalographic Silence." *Neurology*, 20, 1970, 525-533. For a fuller discussion of brain death and cerebral Death, see: Veatch, Robert, "The Whole-Brain-Oriented Concept of Death: An Outmoded Philosophical Formulation", *Journal of Thanatology* 3, 13 (1975) and his, *Death, Dying and the Biological Revolution*, Yale U. Press, New Haven, 1976, pp. 21-76; Brierley, J.B. *et al.*, "Neocortical Death after Cardiac Arrest", *Lancet*, Sept. 11, 1971 pp. 560-565; Capron, Alexander Morgan and Kass, Leon R., "A Statutory Definition of the Standards for Determining Human Death: An Appraisal and a Proposal", *U. of Pennsylvania Law Review*, 121, Nov. 1972, p. 97. For further proof (if any is required) that this paper's discussion of death and brain death has merely skimmed the surface of a very complex, long debated and fascinating subject, see the collection of readings edited and introduced by Antony Flew in his, *Body, Mind and Death*, Macmillan, N.Y., 1964. The readings, "... have been selected in the light of the editorial conviction that the fundamental issues outstanding are primarily philosophical rather than scientific. Yet, equally certainly, they are issues that can be resolved satisfactorily only by a philosophy receptive to a scientific outlook, and informed by scientific knowledge." (p. 2). For a scientific (but very readable) history of the human brain, see Carl Sagan's, *The Dragons of Eden*, Ballantine Books, N.Y., 1977.

95. Ariès, Philippe, *Western Attitudes Toward Death, from the Middle Ages to the Present*, Johns Hopkins U. Press, Baltimore, 1974, p. 88.
96. Diggory, J. C., and Rothman, D. Z. "Values Destroyed by Death", *Journal of Abnormal and Social Psychology*, 63, 1961, 205-210.
97. Gellman, Derek, M.D. *Dimensions in Health Services* 52, Nov. '75, p. 23.

One of the central points argued earlier in this paper in dealing with the sanctity of life is worth recalling here, and has been well stated by Richard McCormick: "In the past the Judeo-Christian tradition has attempted to walk a balanced middle path between medical vitalism (that preserves life at any cost) and medical pessimism (that kills when life seems frustrating, burdensome, 'useless'). Both of these extremes root in an identical idolatry of life—an attitude that, at least by inference, views death as an unmitigated, absolute evil, and life as the absolute good. The middle course that has structured Judeo-Christian attitudes is that life is indeed a basic and precious good, but a good to be preserved precisely as the condition of other values. It is these other values and possibilities that found the duty to preserve physical life and also dictate the limits of this duty. In other words, life is a relative good, and the duty to preserve it a limited one." ("To Save or Let Die", *Journal of the American Medical Association*, 229, 2, July 8, 1974, p. 174).

98. Weber, Leonard J., *op. cit.*, (note 79) p. 83.
99. McCormick, Richard A., "The Quality of Life, The Sanctity of Life", *Hastings Center Report* 8(1), 1978, p. 35.

100. Fletcher, Joseph, "The Right to Live and the Right to Die", *The Humanist*, 34(4), Aug. '74, p. 13.
101. Morrison, Robert S., "The Dignity of the Inevitable and Necessary", in Peter Steinfels and Robert Veatch (editors) *Death Inside Out*, Harper and Row, 1974, p. 98.
102. Englehardt, H. Tristram, "The Counsels of Finitude", in *Death Inside Out*, op. cit. (note 101), p. 124.
103. Fletcher, Joseph, op. cit., (note 100) p. 13.
104. Kübler-Ross, Elisabeth, *Death, The Final Stage of Growth*, Prentice Hall Inc., Englewood Cliff, N.J., 1975, p. 6.
105. Zilboorg, G., "Fear of Death", *Psychoanalytic Quarterly*, 12, 1943, p. 467.
106. Ramsey, Paul, "The Indignity of Death with Dignity", in *Death Inside Out*, op. cit. (note 101), p. 82.
107. Kluge, Eike-Henner W., *The Practice of Death*, Yale University Press, New Haven, 1975, p. 155.
108. Barth, Karl, *Church Dogmatics*, Vol. 3, Part 4, T. Clark, Edinburgh, 1961, p. 246.
109. For a recent and excellent application of this and other ethical principles (beneficence and justice), see, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report. Ethical Principles and Guidelines for the Protection of Human Subjects of Research*, DHEW Publication No. (OS) 78-0012, Wash. D.C., 1978.
110. Callahan, Daniel, *The Tyranny of Survival and other Pathologies of Civilized Life*, Macmillan, 1973, p. 164.
111. Ramsey, Paul, *The Patient as Person*, op. cit. (note 90).
112. Hauerwas, Stanley, "Must a Patient be a 'Person' to be a Patient?", *Connecticut Medicine*, 39 (12), 1975, p. 185.
113. Ibid., p. 816.
114. Bok, Sissela, "Who Shall Count as a Human Being? A Treacherous Question in the Abortion Discussion", in Robert L. Perkins (ed.), *Abortion, Pro and Con*, Schenkman, Cambridge, Mass., 1974, p. 96.
115. Ibid., p. 97.
116. Ibid., p. 97.
117. For more on this point and on the subject of witches, see the insightful historical study by H. Trevor-Roper, *The European Witch-Craze of the*

16th and 17th Centuries, Penguin Books, 1967. He notes, "The concepts of a pact with the Devil, of night-riding to the sabbat, of *incubi* and *succubi*, may derive from the pagan folk-lore of the Germanic peoples. But the weaving together of these various elements into a systematic demonology which could supply a social stereotype for persecution was exclusively the work, not of Christianity, but of the Catholic Church . . . Like the Jew, the witch became the stereotype of the incurable nonconformist; and in the declining Middle Ages the two were joined as scapegoats for the ills of society . . . In the mid-sixteenth century, the craze was revived and extended, and the years from 1560 to 1630 saw the worst episodes in its long history. It seems incontestable that the cause of this revival was the intellectual regression of Reformation and Counter-Reformation, and the renewed evangelism of the rival Churches." (pp. 114-116) The reader may feel that I have belaboured at too great length the subject of witches and "personhood". However it seemed a useful exercise in order to demonstrate that it may be more facile than historically accurate to assume that denial of "personhood" has always been the cause or focal point of the denial of rights to certain peoples and groups.

118. Hostler, John, "The Right to Life", *Journal of Medical Ethics*, 3, 1977, p. 143.
119. Maclean, Elizabeth A. "Dignity", *Journal of Medical Ethics*, 3, 1977 p. 41.
120. *Ibid.*, p. 41.
121. Shaw, Anthony, "Defining the Quality of Life", *Hastings Center Report* 7 (5), Oct. 1977, p. 11.
122. *Ibid.*, p. 11.
123. *Ibid.*, p. 11.

For contexts wider than the one under consideration here one would even agree (enthusiastically) that not only does a subject's quality of life considered fully include such (environmental) factors, but so does his personhood. A fuller "definition" of personhood than the minimal one needed here would go well beyond the *capacity* to relate, and would include *actual* relationships somewhere near the center of what a person is and what makes a person. Therefore we would generally agree that, ". . . a person is not identical with merely the qualities inhering in a particular mind-body having certain spatiotemporal boundaries. Because we identify specific persons by pointing to their bodies or by referring to their performances, the *logic* of personal identity requires such boundaries; but this does not entail that the *nature* of personhood be similarly restricted. Personhood inheres in a complex network of relationships, not only in the aforementioned qualities. . . . for there is a rationally interpersonal life with numerous relationships uniting them in fealty to others and unifying their lives by loyalty to ideals . . . they prosecute ideals, they share achievement and failure, they love and are loved . . . were there no such relationships, human beings would be no more than highly complex organisms." Robert Hoffman, "Death and

Dignity", in Marvin Kohl (ed.), *Beneficent Euthanasia*, Prometheus Books, N.Y., 1975, p. 75.

An excellent philosophical analysis of similar themes is found in Brian Wicker's *Culture and Theology* (Sheed and Ward, London, 1966). Particularly relevant to notions of personhood are pages 48-101, in which he discusses Merleau-Ponty, Wittgenstein and Marx. He demonstrates that, "For Merleau-Ponty, perceptual experience presents us with a world which is not standing over against us, but is first of all that in which we inhere, and which gives us our own identity as individuals. From this position it is possible to go on to show (with Wittgenstein) that this world is more than something given in perception: it is a world structured, to its very roots, by our own capacity for, and use of, language. We live in a linguistic world: and it is this world which gives us our own humanity. Finally, Marx adds to this insight the understanding that the linguistic world becomes ours only because we are trying all the time to transform it, to humanize it, in the process of ensuring our survival in it—that is, by the economic process." (p. 15).

One crucial implication of all this for our concerns is that it would be simplistic indeed for either medical decision-making or health policy choices (and any translation of same into law) to always assume a polarity between the individual and society, to assume that those decisions and choices must always favor one at the expense of the other. As Daniel Callahan writes, "The great threat to the possibility of a social ethic for a technological society is less the absence of all values than the triumph of one value over all others. Both individualism and survival [of the community] are struggling to achieve that position, with a striking degree of success. Nothing is more important than to deny both the triumph they seek." *The Tyranny of Survival and Other Pathologies of Civilized Life*. Macmillan, N.Y., 1973, p. 135.

124. One cannot fail to be enormously impressed by the heroic and compassionate care extended to seriously defective newborns and infants by parents and other members of families, as well as by the staff of institutions. And, undoubtedly such experiences provide families and institutional staffs with the opportunity for learning and extending compassion, love and fidelity with a degree of intensity and responsibility provided by few other experiences in life.

One physician, after listing the many possible serious defects which newborns can have, writes, "I treated a boy who had half of these things plus a few others. He has had more than twenty-five operations. I see him and his family in the community about once a week. They are a great family and consider the boy and his problems to be the best experience life has offered them. The boy is a delight. He has strengthened the family and has taught them compassion and understanding." (C. Everett Koop, M.D., *The Right to Live, The Right to Die*, Tyndale House Publishers, Inc., Wheaton, Illinois, p. 23).

Another physician expressed much the same thought, but this time applied to the staff of institutions. "The institution was immaculate. Someone in the institution was capable of relating closely to every child,

and at every bedside as we made rounds there would be a staff member who could tell us the child's history . . . Severe hydrocephalics and markedly obtunded, neurologically damaged children were called by name and regarded as individuals. Their disease and related irascibility was understood, explained away and assuaged by acts of comfort." (Eugene F. Diamond, M.D., "Quality vs. Sanctity of Life in the Nursery", *America*, 135, Dec. 4, 1976, p. 397).

Yet one cannot avoid two nagging suspicions. One is that in *some* (possibly a very small minority) of these cases, if decisions had been made soon after birth or later not to treat, due to a reliable diagnosis of severe defects and a reliable prognosis of continued and largely intractable pain and suffering (due for instance to continuing and drastic surgical interventions), they may well have been decisions for the benefit of those children. The second and related suspicion is that *sometimes* such decisions are not made at least partially because we, the healthy, derive meaning, purpose, compassion and satisfaction from experiences which can have no such positive features for those defective infants and children (as well as adults) who provide us with these opportunities.

125. Hellegers, André F., "Relating is the Criteria for Life", *Ob. Gyn. News*, Oct. 15, 1974, p. 48.

126. Fried, Charles "Terminating Life Support: Out of the Closet", *New England Journal of Medicine*, Aug. 12, 1976, p. 390.

Eugene Diamond M.D., notes the difference in perspective, and therefore in decisions made between those on the scene when the defective child is born (especially those in intensive care units), and those with responsibility for long term and follow up care. The former (he writes), ". . . are inclined to have a low frustration tolerance and to doubt the validity of large investments of professional time and energy to realize small returns of stable or slightly altered function." But the latter group (he writes) are prepared to settle for those smaller returns. (Eugene Diamond, M.D. "Quality vs. Sanctity of Life in the Nursery", *America*, 135, Dec. 4, 1976, p. 397).

127. Callahan, Daniel, *The Tyranny of Survival and other Pathologies of Civilized Life*, op. cit., (note 110) p. 234.

128. *Ibid.*, p. 288.

On the other hand it is not difficult to think of some hypothetical eventualities in which "burden on others" by allowing a defective child to be born could become so great that it would be morally justified to force its mother to abort it. One such hypothetical example would be that of a foetus discovered by tests to have a severe and contagious infection, which disease would release a deadly and uncontrollable plague into the world if the child were allowed to be born.

Less hypothetical and more urgent are questions and cases concerning the burden, not to "society" but to the severely defective potential child if allowed to be born. One factor which raises this moral question with some urgency are the suits for "wrongful life" initiated in

recent years in a number of countries, on the grounds that life itself in some circumstances constitutes an injury to the living person. Though to my knowledge these suits have so far failed, they have in their successful initial stages raised some serious moral as well as legal questions some of which have implications for our issue here. The basic moral question is of course whether it may be an injustice to a potential child known to be severely defective, to cause or allow him to be born. In these torts it has been argued that when great and intractable suffering or harm can be predicted before birth for that child once born, life itself can be considered not a gift but an injury, and there well may be a *duty* not to give that person existence. In my view it is an argument not without some merit.

While society should not be allowed to forbid the procreation and birth of genetically "imperfect" bodies and minds, it would however seem equally legitimate and quite consistent to argue that couples may sometimes have a "genetic" responsibility, especially to the potential children, to not procreate. This is surely the case when the couple has been provided with genetic information about themselves indicating the strong likelihood that their offspring will be seriously defective because of genetic defects in one or both parents. The sort of "genetic roulette" involved in procreating regardless and hoping for the best, would seem to be almost as distasteful as state eugenic programs which forbid imperfections.

I say "almost" because the latter seems the more potentially dangerous of the two approaches, which in turn leads one to resist any temptation to transform a parental *responsibility* (to weigh the information and sometimes freely decide not to procreate) into a strict duty or law (absolutely forbidding procreation or insisting upon abortion).

129. Bok, Sissela, "Who Shall Count as a Human Being?" op. cit., (note 114) p. 94.

See also André E. Hellegers M.D., "The Beginnings of Personhood: Medical Considerations", *Perkins Journal*, 27,1, 1973. He writes, "Terms like 'personhood' . . . have no meaning in biology. What evidence science can bring to the debate must be restricted to that in which it has competence. This competence is restricted to describing biological facts." (p. 11) ". . . I do not consider the abortion debate a medical debate at all . . . In the abortion debate the physician can only state his own perceptions on value judgements about undoubted biological human life . . . one does well to realize that those physicians who decide to perform the abortion do so as a reflection of their personal value perception of unborn human life, rather than on biological or medical fact." (pp. 14-15)

130. See *Roe v. Wade*, 93 S. Ct. 705 (1973) p. 730. *Morganthaler v. The Queen*, (1975) 53 D.L.R. (3d) p. 203.
131. See Kluge, E. H-W., "The Right to Life of Potential Persons", *Dalhousie Law Journal*, Jan. 1977, pp. 837-848.

- 132 See for instance, *Montreal Tramways Co. v. Léveillé* (1933) 4 D.L.R. 337 (for the approach of civil law); *Smith v. Fox* (1923) 3 D.L.R. 785 (Ont. S.C.); *Duval v. Seguin*, 26 D.L.R. 3rd 418 (Ont. S.C. 1972); California Civil Code, 3. 29. This latter states, "A child conceived but not yet born is deemed an existing person so far as may be necessary for its interests in the event of subsequent birth."

See also *In re Holthausen* 26 N.Y.S. 2d 140, at p. 143 (Sur. Ct. 1941), in which a New York court stated, "It has been the uniform and unvarying decision of all common law courts in respect of estate matters for at least the past two hundred years that a child en ventre sa mere is 'born' and 'alive' for all purposes for his benefit."

133. Without resorting to "definitions" of person, law does of course consider the question, "Is this a person with rights and duties in law", a central and decisive one. One seemingly representative view of the subject is that of Howard J. Taubenfeld ("The Beginning of Personhood: Legal Considerations", *Perkins Journal*, 27,1, 1973, pp. 16-19) who writes that, "... there may be a number of answers within the legal system. The analyst needs to ask the context in which the answer to the question, 'Is this a person?' is sought... And the law most appropriately asks, 'Is this a person for purposes of this set of legal considerations?'. The answer may well be yes for some and no for others, as the society has weighed and balanced conflicting interests..." (p. 17). "For purposes of that statute or document the meaning can be found, but that doesn't necessarily define the term for the law..." (p. 18) "... the answers depend not on mystical, metaphysical, or even fully on medical analysis, but on a balancing of conflicting interests and rights and duties..." (p. 19).

An important Canadian example of the way the context or particular law contributes to a court's decision on the question of personhood, is the Supreme Court's judgment in *Montreal Tramways Co. v. Léveillé* (supra, note 132), an appeal based on the *Quebec Civil Code*. The Company argued that the child (born with a deformity suffered while as yet unborn) was not really a person when injured, but only a part of her mother. But the Court rejected that defence, and Mr. Justice Lamont finding in favour of the plaintiff noted that, "... I am of the opinion that the fiction of the civil law must be held to be of general application. The child will, therefore, be deemed to have been born at the time of the accident to the mother. Being an existing person in the eyes of the law it comes within the meaning of 'another' in art. 1053, and is, therefore entitled through its tutor to maintain the action." (Ibid., p. 346)

It has been maintained that, "In *Montreal Tramways Co. v. Léveillé* ... judicial notice was taken of the fact that in some areas the law has long recognized an unborn infant as a person". (Weiler, Karen M. and Cotton, Kathleen, "The Unborn Child in Canadian Law", *Osgoode Hall Law Journal*, 14, 3, Dec. 1976, p. 653). Whether or not that might be claiming too much for "what the law has long recognized", this particular judgment at least (based in large part on an argument of natural justice) did acknowledge the existence of a foetal person meriting the compensation extending to injured persons.

134. See for instance Kluge, E. H. W., "The Right to Life of Potential Persons", op. cit., (supra, note 131) p. 842. Kluge writes, "... an individual may be counted as a person if and only if he is now thus self-aware or can acquire such an awareness without it being necessary that he undergo a fundamental constitutive change in his physiological make-up in order to have such an awareness."
135. to some extent the argument from potential personhood either begs the question or concedes the point that the foetus is not now a person. If one argues that a foetus has the *potentiality* to become a person, one has conceded that it *isn't now* one. If one maintains that the foetus has the potentiality *of* a person, one begs the disputed question—whether foetuses are persons.
136. Bok, Sissela, op. cit., (note 114) p. 99.
137. See for instance, T. S. Clements, *Science and Man: The Philosophy of Scientific Humanism*, Charles Thomas, Springfield, Ill., 1968 (ch. 4); G. G. Simpson, *Biology and Man*, Hancourt, Brace and World, N.Y., 1969.
138. Fletcher, Joseph, "Indicators of Humanhood: A Tentative Profile of Man" *Hastings Center Report*, 2, 5, Nov. 1972, pp. 1-4; "Four Indicators of Humanhood — The Enquiry Matures," *Hastings Center Report*, 4, 6, Dec. '74, pp. 4-7.
139. Fletcher, Joseph, "Indicators of Humanhood: A Tentative Profile", *Ibid.*, p. 1.
140. Fletcher, Joseph, "The Right to Die", *Atlantic Monthly*, April 1968, p. 64.
141. Engelhardt, H. T., "Medicine and the Concept of Person", a paper read as part of the Matchette Foundation Series, "The Expanding Universe of Modern Medicine", The Kennedy Institute and the Dept. of Philosophy, Georgetown University, Washington D.C., Nov. 19, 1974, p. 16. For much of what follows on the subject of person I am indebted to the analysis of H. T. Engelhardt. The position I propose on this point is substantially similar to his.
142. *Ibid.*, p. 13.
143. Engelhardt, H. T., "The Beginning of Personhood: Philosophical Considerations", *Perkins Journal* 27,1, 1973, p. 21.
144. For instance by Michael Tooley, in "A Defense of Abortion and Infanticide", in Joel Feinberg (ed.), *The Problem of Abortion*, Wadsworth Pub. Co., Belmont, Calif., 1973, pp. 51-91.
145. Weber, Leonard, *Who Shall Die?* op. cit., (note 79) p. 85.
146. Ramsey, Paul, "Euthanasia and Dying Well Enough", *Linacre Quarterly* 44, 1, Feb. '77, p. 44.

147. Pope Pius XII, AAS 49 (1957) 1031-32.
148. As cited in John F. Dedek, *Contemporary Medical Ethics*, Sheed and Ward, N.Y., pp. 201-205.
149. Ibid., p. 206-214.
150. Proceedings, A.M.A. House of Delegates, December, 1973.
151. Code of Ethics, Approved by General Council of C.M.A., June 1975.
152. Healy, Edwin, *Medical Ethics*, Loyola University Press, Chicago, 1956, p. 67.
153. Veatch, Robert, *Death, Dying and the Biological Revolution*, Yale U. Press, New Haven, 1976, especially pp. 105-115. In much of what follows in this section I am indebted to his exposition.
154. Ibid., p. 106.
155. Ibid., p. 107.
156. Kelly, Gerald, *Medico-Moral Problems*. The Catholic Hospital Association, St. Louis, 1958, p. 129.
157. Veatch, Robert, op. cit., (note 153) p. 109. See also Paul Ramsey, *The Patient as Person*. op. cit., (note 90) pp. 136-144.
158. If a presently noncompetent but once competent patient expressed a clear wish while coherent (orally or in writing) as to the conditions under which he wished life saving or supporting treatment begun, continued or stopped, then that wish should be respected as a "reason still valid to himself". In our view no compelling argument can be advanced in favour of cancelling such previously expressed wishes because of one's present altered state. Such an argument would ignore the important distinction to be made between those *never* competent and those *previously* competent.
159. Hunter v. Brown, 4 Wash. App. 899, 484 p. 2d 1162 (1972). See also Berkey v. Anderson, 1 Cal. App. 3d 799, 805, 82 Cal. 67, 68 (1969).
160. *Globe and Mail* (Toronto), June 20, 1978, p. 3.
161. Veatch, Robert, op. cit., (note 153) p. 111.
162. Ibid., p. 112.
163. See Richard McCormick, "The Quality of Life, the Sanctity of Life", op. cit., (note 99) p. 33.
164. Ibid. p. 35, citing from, "In the Matter of Karen Quinlan, an Alleged Incompetent," A-116, March 31, 1976, p. 24.

165. It should be noted by way of preliminary that according to the "irreversible cessation of total cerebral function" standard discussed earlier (see p. 62), Karen may perhaps be dead as a person already, though she is able to breathe spontaneously. But since, as also noted, such a standard may not be generally acceptable (it obviously is not to her parents and physicians), it would be "prudent" to consider Karen as being still alive for the purpose of related policy decisions, such as whether or not to continue life support treatment. This in fact is how she was and is considered by her parents and physicians. But as we have already noted at length, the presence of death, the cessation of personhood, is not the only case in which treatment may be stopped. Another reason is that further treatment could not be useful, would only prolong dying.
166. Ramsey, Paul, "Prolonged Dying: Not Medically Indicated," *Hastings Center Report*, 6,1, Feb., 1976, p. 16.
167. Weber, Leonard, op. cit., (note 79) p. 92.
168. McCormick, Richard T., op. cit., (note 99) p. 35.
169. Or perhaps still more accurately "only caring for the dying", as Paul Ramsey labels it. See his, *The Patient as Person*, pp. 113-164.
170. Veatch, Robert, op. cit., (note 153) p. 77.
171. Ramsey, Paul, "Euthanasia and Dying Well Enough", *Linacre Quarterly*, 44 (1977), p. 35.
172. Louisell, David, "Euthanasia and Biathanasia: On Dying and Killing," *Catholic University Law Review*, 22, Summer 1973, p. 730.
173. See for instance Fletcher's, "The Patient's Right to Die," *Harper's*, October 1960, pp. 141-142; "The Right to Live and the Right to Die: A Protestant View of Euthanasia", *The Humanist* (34) 4, July, August 1974, pp. 12-15; "Euthanasia and Anti-Dysthanasia", chapter 9 of his *Moral Responsibility*, Westminster, Philadelphia, 1967, pp. 141-160.
174. Ramsey, Paul, *The Patient as Person*, op. cit., p. 151, see also his, "Euthanasia and Dying Well Enough", op. cit., p. 38.
175. *On Dying Well: An Anglican Contribution to the Debate on Euthanasia*. Church Information Office, Church House, Dean's Yard, London, England, 1975, p. 48.
176. Saunders, Cicely, "The Moment of Truth: Care of the Dying Person", in Francis G. Scott and Ruth M. Brewer. (editors), *Confrontations of Death*. Oregon Center for Gerontology, Corvallis, Oregon, 1971, p. 119.
177. Louisell, David, op. cit., (note 172) p. 731.
178. Ramsey, Paul, "Euthanasia and Dying Well Enough", op. cit., (note 146) p. 40.
179. *On Dying Well*, op. cit., (note 175) p. 40.

180. Rachels, James, "Active and Passive Euthanasia", *The New England Journal of Medicine* 292 (Jan. 9, 1975) pp. 78-80.

181. *Ibid.*, p. 79.

182. See for instance Tom L. Beauchamp, "A Reply to Rachels on Active and passive Euthanasia", *Social Ethics*, McGraw Hill, 1977, pp. 67-74; James Childress, "To Kill or let Die", unpublished paper; Robert Veatch, *Death, Dying and the Biological Revolution*, op. cit., (note 153) pp. 80-93; Richard A. McCormick, "Notes on Moral Theology", *Theological Studies*, 37, (3) (1976), pp. 100-107; Gilbert Meilander, "Killing and Allowing to Die", *Theological Studies* 37 (3), 1976, 467-470; P. J. Fitzgerald, "Acting and Refraining", *Analysis*, 27,4, March 1967, pp. 133-139.

183. Childress, James, op. cit., (note 182), p. 3.

That is, once motives are put aside we might find morally relevant distinctions in their actions and omissions on the basis of other factors such as duty to act, methods used and so forth. Put in terms of a simple statement, as applicable in law as in morals, one might then express it this way: If there is no difference between killing and allowing to die, it is because one has a duty not to allow to die; but if there is *no* such duty then there is a difference between them because there *is* a duty not to kill. P. J. Fitzgerald (op. cit., note 182) expresses the same point in this manner: "This then points to one moral difference between acting and not-acting, where both will cause harm. Acting seems to start with a presumption against it: *e.g.* killing is *prima facie* wrong. Not-acting starts without any such presumption, and it is only by establishing a duty to act that we show that not-acting is wrong. Killing needs to be justified; not saving life does not." (p. 136)

184. Childress, James, op. cit., (note 182), p. 4.

185. Fletcher, Joseph, "The Right to Live and the Right to Die", op.cit., (note 173) p. 14.

186. Ramsey, Paul, *The Patient as Person*, op. cit., (note 90) p. 153.

187. Beauchamp, Tom L., "A Reply to Rachels on Active and Passive Euthanasia", op. cit., (note 182) p. 71.

See also Sissela Bok, who notes that even, "The provision that the patient be dying . . . is not without ambiguity. In a sense, any patient who is seriously ill might or might not be dying. And even in these cases where death seems *likely* in days or weeks, its probability varies. Thus one patient may be thought of as having one chance in a hundred of surviving, the estimate based on a comparison with past cases. Another may be considered to have two chances in a hundred, or five, of surviving. Where does one draw the line and determine that the patient is definitely dying? Nowhere in the long history of disagreement among doctors about the certainty of the prognosis of death has this question been resolved." From "Euthanasia and the Care of the Dying", in John

A. Behnke and Sissela Bok (editors), *The Dilemmas of Euthanasia*, Anchor Books, Doubleday, N.Y., 1975, p. 3." See also Brown, Norman *et al.*, "The Preservation of Life", *Journal of the American Medical Association*, 21, 1970, 76-81.

188. Veatch, Robert, *op. cit.*, (note 153) p. 89.

189. Bok, Sissela, "Euthanasia and the Care of the Dying", *op. cit.*, (note 187), p. 8.

It is of course impossible and unnecessary to deny that in many *individual cases* it may well be more "humane" not simply to cease treatment, but to actively hasten death. Referring to babies born with spina bifida, and to programs (such as those of Dr. John Lorber) which select for treatment those newborns with the best prognoses, while allowing those with no chance for "normal" lives to die, one commentator writes, "There is a blatant inconsistency in the attitudes of doctors who operate a policy of 'selection'. The whole aim of such a policy, and the hope of all those who are a party to the decision to put that policy into operation, is that the child should be allowed to die quickly. Yet, having made this selection, the same doctors, along with the baby's parents, are prepared, or are forced, to stand back, take no further action, and watch the child take three, six or sometimes as many as nine months to die. In the most unfortunate of circumstances the child will live on, either in an institution, or cared for by its parents . . . The state of affairs is clearly ironical, and verges on the hypocritical. If a designated aim of medicine is that a child should die, why would it not be more humane to make it die?" Robert Reid, "Spina Bifida: The Fate of the Untreated", *Hastings Center Report*, Aug. 1977, p. 18.

190. Beauchamp, Tom L., *op. cit.*, (note 182) p. 73.

191. Louisell, David, "Euthanasia and Biathanasia: On Dying and Killing", *Linacre Quarterly* 40: 234-258, 1973.

192. Though others argue that the burden of proof should be on those opposing legalization to show that euthanasia is wrong. One of these is Anthony Flew, who writes that the proper question is not, "Why should people be given this new legal right?", but, "Why should people in this matter be restrained by law from doing what they want?" While I disagree with Flew as to which side has the burden of proof, I hope the reasons given above provide adequate answers to his question.

193. On the art of pain control see for instance Cicely Saunders, "The Challenge of Terminal Care", in T. Symington and R. L. Carter (editors), *Scientific Foundations of Oncology*, William Heinemann Medical Books Ltd., London, pp. 673-679; Twycross, R. G. "Diseases of the Central Nervous System: Relief of Terminal Pain", *British Med. Journal* 4: 212, 1975.

It should however be noted that the word (and reality of) pain is considerably more ambiguous, less objectifiable and more multi-faceted than medical journal articles usually acknowledge. "Pain control" is no

doubt a highly advanced art insofar as the target is limited to bodily pain accessible to pain-killing drugs or surgical intervention. But "pain" in other senses is not so objectifiable or manageable. At one level it is a problem of language, as noted for instance by Ivan Illich. "The technical matter which contemporary medicine designates by the term pain even today has no simple equivalent in ordinary speech. In most languages the term taken over by the doctors covers grief, sorrow, anguish, shame and guilt . . ." (*Medical Nemesis*, McClelland and Stewart, Toronto, 1975, p. 97).

Illich has much of interest and relevance to say about the history and "cultural framework" of pain. He notes for instance that, "As long as pain was primarily an experience that had to be faced and suffered, its political function was to set limits to man-made abuses of man by man when these became intolerable. Now an increasing portion of all pain is man-made, a side effect of strategies for industrial expansion . . . the industrial system responds by delivering them medical pain-killers. Pain thus turns into a demand for more drugs, hospitals, medical services . . . no matter what its human, social or economic cost." (p. 94.).

194. Childress, James, op. cit., (note 182) p. 9.
195. Ramsey, Paul, *The Patient as Person*, op. cit., (note 90) pp. 160-164.
196. Ibid., p. 161.
197. Veatch, Robert, op. cit., (note 153) p. 95.
198. Hare, R. M., "Abortion and the Golden Rule", *Philosophy and Public Affairs*, vol. 4, No. 3, Spring 1975, pp. 202-203.
199. Fletcher, Joseph, "The 'Right' to Live and the 'Right' to Die: a Protestant View of Euthanasia", op. cit., (note 173) p. 12.
200. Hauerwas, Stanley, "Rights, Duties and Experimentation on Children: A Critical response to Worsfold and Bartholome", in *Appendix to Research Involving Children*, The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, DHEW Publication no. (05) 77-0005, Washington, D.C. 1977, pp. 5-1 to 5-27, 1977.
201. Particularly in two unpublished papers, "The Definition of Death and the Right to Die" (1976) and "Legalism and Medical Ethics" (1977), and as presented by him in a public lecture during the "Colloquium on Biomedical Ethics", London, Ont., Oct. 27-30, 1977.
202. That there is in fact a difference between the perspectives of law and morals is of course one of the theses of this section of the paper. But an observation made in the Introduction (p. 1) should be recalled here. On the one hand, a judgment about morals is a necessary condition (at least psychologically) for law and punishment to be brought into play. Especially with criminal law one wants to think that the law is making a *moral* claim, and not just a legal claim on one. But on the other hand, a judgment about morals is not a *sufficient* condition. The acts in question

might not be sufficiently harmful; (or) if harmful, the law and legal processes may not be the best means of dealing with them.

203. Ladd, John, "Legalism and Medical Ethics", op. cit., (note 201), p. 7.

See also for instance David Mechanic, "Health and Illness in Technological Societies", *Hastings Center Studies*, 1, 3, 1973, 7-18. He notes that in view of the growing bureaucratization and depersonalization of medicine as an institution, the traditional responses of formulating rules on an *ad hoc* basis, or relying largely on informal solutions out of sight of the public forum are no longer adequate. "Traditionally, we have seen many of the dilemmas as problems to be worked out by patients and their individual physicians in their continuing relationship which was viewed as confidential and intimate. But medicine is now more complex; physician services are more specialized, stratified, and segmented, and a wide variety of non-medical personnel plays an important role in the delivery of patient care . . . The thrust of organizational events is to encourage bureaucratic solutions to the uncertainties and complexities of a changing technology. But, at the same time, people in modern societies are seeking greater autonomy over decisions affecting their own lives." (p. 14)

204. Ladd, John, *Ibid.*, p. 8.

205. This point of course assumes that rules express and articulate rights, or that rights in a sense represent rules (see Ladd, *Ibid.*, p. 9).

206. *Ibid.*, p. 15.

207. For more on this Movement see: "St. Christopher Hospice", *Nursing Times*, July 28, 1967, pp. 2-5; Saunders, Cicely, "When a Patient is Dying", *Nursing Times*, Nov. 13, 1959, pp. 1129-1130; Saunders, Cicely, *Care of the Dying*, Macmillan, London, 1959; Garner, Jim, "Palliative Care: it's the quality of life remaining that matters", *Canadian Medical Association Journal*, 115, July 17, '76, pp. 179-180; Paige, Roberta Lyder; Looney, Jane Finkbner, "Hospice Care for the Adults", *American Journal of Nursing*, Nov. 1977, pp. 1812-1815.

208. See for instance these writings by Kübler-Ross: *On Death and Dying*, Macmillan, N.Y., 1969; "Dying with Dignity", *The Canadian Nurse*, 67, 10 (Oct. 1971), pp. 31-35; "The Family Physician and the Dying Patient", *Canadian Family Physician* (Oct. 1972), pp. 79-83; *Death the Final Stage of Growth*, Prentice Hall, Englewood Cliffs, N.J., 1975.

209. Ladd, John, "Legalism and Medical Ethics", op. cit., p. 15.

It is sometimes argued or suggested that in today's impersonal, complex and highly technical medical bureaucracy qualities such as compassion are more or less secondary and a luxury compared to the need to secure rights in formal structures and processes. Yet even one who could be linked with aspects of that view acknowledges that, "It is ironic that now that medicine has developed the capacity to be helpful in a variety of ways, it has lost much of its capacity to communicate compassion, so

central to the healing process. Indeed, even from a purely technical perspective, the effectiveness of medical care depends on the patient's cooperation . . . Failures in communication and empathy not only harm a vital function of medical care, but also diminish the opportunities for technical quality and effectiveness." David Mechanic, *op. cit.*, (note 203), p. 9.

210. See Urmson, J. O., "Saints and Heroes", in Joel Feinberg (ed.) *Moral Concepts*, London: Oxford University Press, 1961, pp. 60-73. (Cited by Ladd, *op. cit.*, p. 17).
211. Ladd, John, "Legalism and Medical Ethics", *op. cit.*, p. 18.
212. *Ibid.*, p. 21.
213. *Ibid.*, p. 25.
214. Burt, Robert A., "The Limits of Law in Regulating Health Care Decisions", *Hastings Center Report*, 7, 6, Dec. '77, p. 29. The analysis which follows on the subject of "objectivity" and "detachment" is largely based on Burt's.
215. *Ibid.*, p. 30.
216. *Ibid.*, p. 30.
217. *Ibid.*, p. 32.
218. *Ibid.*, p. 32.
219. John Ladd (in his "The Definition of Death and the Right to Die", *op. cit.*, p. 14) gives the name "ideal rights" to what for instance H. J. McCloskey calls, "welfare rights". See J. J. McCloskey, "Rights", *Philosophical Quarterly* 15 (1965), pp. 115-127.
220. Ramsey, Paul, "Euthanasia and Dying Well Enough", *op. cit.*, (note 146) p. 45.
221. See, *New England Journal of Medicine*, 295, August 12, 1976. Rabkin, Mitchell *et al.*, "Orders not to Resuscitate", p. 364, Pontoppiden, H. *et al.*, "Optimum Care for Hopelessly Ill Patients", p. 362.
222. Fried, Charles, "Terminating Life Support: Out of the Closet", *New England Journal of Medicine* 295, Aug. 12, 1976, p. 390.
223. It should be noted that a great number of hospitals, intensive care units, palliative care units or other groups attached to hospitals are presently working on such guidelines. In Canada one such group I am aware of is the Medical/Legal/Theological Society, composed largely of physicians, nurses and chaplains attached to Foothills Hospital in Calgary, Alberta. Another is a group of staff members attached to McMaster University Medical Centre, in Hamilton, Ontario.
224. Fried, Charles, *op. cit.*, p. 390.

225. Shannon, Thomas A., "What Guidance from the Guidelines"? *Hastings Center Report*, 7, 3, June 1977, p. 30.
226. *Ibid.*, p. 30.
227. Culliton, Barbara J., "Helping the Dying Die: Two Harvard Hospitals Go Public with Policies", *Science*, 193, 17 Sept. 1976, pp. 1105-1106.
228. *Superintendent of Belchertown State School vs. Saikewicz*, Massachusetts Supreme Judicial Court No. 5JC-711, 1977.
229. As regards competent patients, the U.S. decision which set the standard for refusal of treatment (in the context of informed consent) was a 1960 decision by the Kansas Supreme Court:

Anglo-American law starts with the premise of thorough-going self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery or other medical treatment. A doctor might well believe that an operation or form of treatment is desirable or necessary but the law does not permit him to substitute his own judgment for that of the patient by any form of artifice or deception (*Natanson v. Kline*, 186 Kan. 393, 350 P. 2d, 1093 [1960]).

This right for competent patients is equally clear in Canada. See *Marshall v. Curry* (1933) 3 D.L.R. 260 (N.S.S.C.).

230. For more on this point see the detailed and insightful study by Paul Ramsey, "The *Saikewicz* Precedent: What's Good for an Incompetent Patient?", *Hastings Center Report*, 8, 6, (Dec. 1978) pp. 36-42. Ramsey notes that, "... we may ask whether the court in reaching for grounds for its substituted judgment did not exceed its grasp. In substituting judgment for this never-competent patient, it set aside the standard of a normal child patient, who also cannot understand the pain and would have to be restrained during prolonged treatment. Attempting to get at *Saikewicz's* 'subjective' standard, I shall suggest, the court treated him *as if* he were a competent patient who then would 'reasonably' take into account the fact that he was incompetent!" (p. 36). Later Ramsey adds, "This quest [of the court's, i.e. to bring the substituted judgment into step with the value and desires of the affected individual] means that the substituted judgment must necessarily be the court's subjectivity, little or not at all constrained by proposed objective tests. Joseph Saikewicz's 'subjectivity' was not *found* by any test the court thought pertinent." (p. 39).

Ramsey rightly observes that, "*Ascription*, not *discovery* of an interest in the incompetent whose case is before the court becomes the meaning of the substituted judgment doctrine." (p. 37). He goes on to add that the question as to what Saikewicz would have decided is an improper question because the court's substituted judgment is not anchored in an *objective* finding or discovery about that incompetent patient. (see his note 6).

231. Curran, William J., "The Saikewicz Decision", *New England Journal of Medicine*, March 2, 1978, p. 500.
232. Annas, George, "The Incompetent's Right to Die: the Case of Joseph Saikewicz", *Hastings Center Report*, 8, 1, Feb., 1978, p. 23.

On the other hand, in fairness to Annas we should note that elsewhere ("After Saikewicz: No Fault Death", *Hastings Center Report*, 8, 3, June '78, 16-18) he maintains that the scope of the Saikewicz case is much narrower and more specific than many of those hostile to it realize. In his view, "The scope of the case is properly limited to the incompetent patient (adult or child) for whom a life-prolonging treatment is available that is used on some patients as standard medical procedure and that is opposed by both the family and the physician because they do not believe the treatment is in the best interests of the patient (p. 17)." In such cases the patients are not terminally ill, and further treatment is not futile, but discontinuing treatment is being considered, "... because the physician and family do not believe that the patient's 'quality of life' justifies further treatment . . . (p. 17)." The real issue in these cases (he argues) is not really "medical" at all, and therefore ought to be resolved in courts of law. Cases which remain for the physician to resolve and act upon without resorting to the courts are those involving the discontinuing of treatment for the terminally ill. Since there has never been a criminal indictment for discontinuing treatment of a terminally ill adult, and since under the circumstances, the only important question is prognosis and feasible treatments, the risk of prosecution is almost nonexistent and the questions are medical in nature. Accordingly, I would argue that it is the physician's duty as a professional to make such determinations (but only with consent if the patient is competent) and act upon them without seeking immunity (p. 17)."

Annas may well be correct in his analysis of the real scope of the Saikewicz case, but I am not convinced that cases and decision making can be as neatly and as hermetically categorized into either "properly medical" decisions if the patient is terminally ill, or "non-medical" decisions if the issue turns (partly) on quality of life factors. The thrust of my own argument has been that there is a very large medical and "non-subjective" quotient involved even in quality of life decision making and the application of factors such as prognosis, patient's perspective, patient's benefit and "reasonable person" judgment.

233. Curran, William, op. cit., (note 231) p. 500.
234. Relman, Arnold S., (M.D.), "The Saikewicz Decision: Judges as Physicians", *The New England Journal of Medicine*, March 2, 1978, p. 508.

Such fears may not be exaggerated in the light of the fact that six cases have been heard by Massachusetts courts in the wake of the Saikewicz decision in the roughly six month period between the decision (November 1977) and June 1978. Annas may be correct when he notes (in, "After Saikewicz: No Fault Death", see note 232 above) that only

one of those six cases is the type of case the Court was thinking of. Nevertheless the other cases were in fact heard by the courts as well, and an unhealthy climate of hostility and fear has clearly taken root in that jurisdiction and elsewhere as a result of the Saikewicz decision.

235. The group met in California and brought together 20 persons from various disciplines: medical, nursing, law, sociology, ethics, economics, social work, anthropology and the news media. See A. R. Jonsen *et al.*, "Critical Issues in New-born Intensive Care: A Conference Report and Policy Proposal", *Pediatrics* 55, 6, June 1975, pp. 756-768.
236. *Ibid.*, p. 760.
237. It should be recalled here that the court in the Saikewicz case professed the opposite view, namely that quality of life concerns should *not* be weighed by the courts, except in the matter of pain.
238. Jonsen (*et al.*), *op. cit.*, p. 762.
239. *Ibid.*, p. 762.
240. See James W. Haviland, "Experiences in Establishing a Community Artificial Kidney Center", *Transactions of the American Clinical and Climatological Association* 77, (1961), pp. 133-34; Sanders, David and Dukeminier, Jesse, "Medical Advance and Legal Lag: Hemodialysis and Kidney Transplantation", *UCLA Law Review*, 15 (1968) especially pp. 371-386; Ramsey, Paul, *The Patient as Person*. Yale U. Press, New Haven, 1970, chapter 7, "Choosing How to Choose: Patients and Sparse Medical Resources", *espec.* pp. 242-259; Reiser, Stanley Joel (M.D.), "Therapeutic Choice and Moral Doubt in a Technological Age", *Daedalus*, 3, 106, Winter 1977, especially pp. 53-55. See also, Katz, Al, "Process Design for Selection of Hemodialysis and Organ Transplant Recipients", *Buffalo Law Review*, 21, 1972, pp. 373-418; Buxton, M. J., "Cost-Benefit Analysis of Long-Term Haemodialysis for Chronic Renal Failure", *British Medical Journal*, 17 May, 1975, pp. 376-379.
241. Haviland, James W., *op. cit.*, (note 240) pp. 133-34.
242. Sanders, David and Dukeminier, Jesse, *op. cit.*, (note 240) p. 378.
243. Ramsey, Paul, *op. cit.*, (note 240) p. 256.
244. *Ibid.*, p. 259.
245. Fuller, L., *The Morality of Law* (revised edition), Yale U. Press, New Haven, 1969, p. 12.
246. This latter view is particularly that of Edmond Cahn in his discussion of the case of *United States v. Holmes* in his, *The Moral Decision: Right and Wrong in the Light of American Law*, Indiana U. Press, Bloomington, 1955, pp. 61-71. For a refutation of this "method", see Ramsey, *The Patient as Person*, pp. 259-266.
247. Ramsey, Paul, *op. cit.*, (note 240) p. 253.

248. Nader, Dr. Laura, "Personal communication", in A. R. Jonsen (*et al.*), "Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal", *op. cit.*, (note 235) p. 760.

Whether Dr. Nader is aware of it or not, much of her observation raises the difficult medical/ethical problem of "statistical lives". That is, if resources allocated to life saving should be used so as to maximize the number of lives saved, or minimize the number of lives lost, then, a cost-benefit analysis typical of economists would say that there is an apparent anomaly in our readiness to expend far more resources saving lives of *known persons in present peril* than on measures to prevent future perils for those unknown. For a helpful treatment of this problem, see Charles Fried, "The Value of Life", *Harvard Law Review*, 82(7):1415-1437, May 1969. He argues that there are important values to consider beyond simple life maximization, and that we have obligations to the presently dying even if the expenditure of resources will not in the long run lead to minimizing the number of lives lost. See also note 252 below.

249. Ramsey, Paul, *op. cit.*, (note 240) p. 274.
250. Jonsen, A. R., *op. cit.*, (note 235) p. 763.
251. Ramsey, Paul, *op. cit.*, (note 240) p. 272.
252. Writing of the cost-benefit analysis applied to the issue of genetic quality of life, Daniel Callahan writes, "We can now, quite literally, put a price on everyone's head, working out the long-term financial costs to individuals and societies of caring for a defective child. But observe a curiosity. It was counted a great advance of the modern mind when a bookkeeping God, with his minutely maintained ledger of good and bad deeds, was noisily rejected. Yet here we are beginning to keep our own books . . . we seem to have forgotten why the bookkeeping God was rejected—because it seemed eminently unjust, insensitive and outrageous that a score card be kept on human lives. Indeed we are even worse than that old God; for at least in his ledger everything was supposedly recorded. But our cost-benefit analysis totes up only one item—what the financial liability will be . . . the kind of cost-benefit analysis which seems to be emerging in genetic calculations goes only in the *cost* direction. It is seemingly assumed that the benefits to a society which decided simply to bear the costs of humane care are either non-existent or simply too intangible to be worth much bother". ("The Genetic Quality of Human Life", in his *The Tyranny of Survival and Other Pathologies of Civilized Life*, Macmillan, N.Y., 1978, p. 226).
253. The otherwise excellent policy paper of Health and Welfare Canada, "A New Perspective on the Health of Canadians" by Marc Lalonde (published in 1974) is a not untypical example of a health policy paper with very few clues on how priorities for the health dollar are established, or what the various implications of policy choices are for other medical services and the wider societal context.

254. Ramsey, Paul, *op. cit.*, p. 274.

255. Bok, Sissela, *New England Journal of Medicine*, Aug. 12, 1976. A number of organizations have distributed other versions of living wills. One version (which refers somewhat vaguely to "physical or mental disability"), is that of the Euthanasia Education Council. Another (somewhat strangely entitled, "Christian Affirmation of Life"), is that of the Catholic Hospital Association (U.S.). This latter is largely a request for prayers and a profession of faith, reserving only a few lines for a request that if there is no reasonable hope of recovery from "physical and mental disability", no extraordinary means be used.
256. For the background and evolution of this Bill, see Michael Garland, "The Right to Die in California—Politics, Legislation and Natural Death", *Hastings Center Report*, Oct. 1976, pp. 5-6.
257. McCormick, Richard, and Hellegers, André, "Legislation and the Living Will", *America*, March 12, 1977, p. 211.
258. The Quinlan case offers a good example of this shift in the doctor/patient relationship away from the patient/family to the physician as primary decision-maker. As McCormick-Hellegers note op. cit., p. 211), it was Mr. Quinlan who went to court to have his request upheld, and not the physician who went to court to have that request denied, the presumption being that physicians have a right to treat a patient unasked and even opposed.
259. Veatch, Robert, "Death and Dying: The Legislative Options", *Hastings Center Report*, Oct. 1977, p. 6.
260. Lebacqz, Karen, "Commentary on Natural Death", *Hastings Center Report*, April, 1977, p. 14.
261. See for instance, Kübler-Ross, *On Death and Dying*, Macmillan, N.Y., 1969; Glaser, B. G. and Strauss, A. L., *Awareness of Dying*, Aldine, Chicago, 1965.
262. See for instance Diana Crane, *The Sanctity of Social Life: Physicians' Treatment of Critically Ill Patients*, Russell Sage Foundation, N.Y., 1975, espec. pp. 46-52, 78-89. See also her "Physicians' Attitudes Toward the Treatment of Critically Ill Patients", *Bioscience*, Vol. 23, August 1973, p. 474.
263. Ibid., and see also for instance a poll conducted by the American Medical Association, in the A.M.A. News, Jan. 24, 1977, as cited by McCormick-Hellegers, op. cit., p. 213. Nurses, as well, appear to respect patient wishes in this regard. See, *Nursing*, Vol. 5, No. 10, Oct. 1975, p. 42. See also, "Physicians Attitude Survey: Doctors and Dying, Is Euthanasia Now Becoming Accepted?", *Medical Opinion*, May 1974, p. 32. Regarding Canadian doctors specifically, see "Euthanasia, 1,700 Doctors Speak Out", *Modern Medicine of Canada*, Vol. 29, No. 7, July 1974, p. 660.
264. Ibid., (notes 262 & 263). See also, A. S. Kraus, *Survey of Health Care Professionals Concerning their Experience with, and Opinions regard-*

ing, *Adult Patients who want to die*, Queens University at Kingston, Ontario, Dept. of Community Health and Epidemiology, 1977.

265. McCormick and Hellegers, op. cit., (supra, note 257) p. 213.
266. Burt, R. A., "Authorizing Death for Anomalous Newborns", in Aubrey Milunsky and George J. Annas, *Genetics and the Law*, Plenum Press, N.Y., 1976, p. 445, as cited by G. Annas in "After Sailewicz: No Fault Death", see above note 232.

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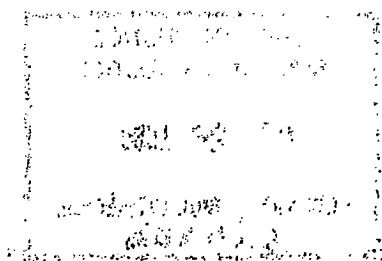
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