"**Source:** ***Sanctity of Life: Or, Quality of Life in the Context of Ethics, Medicine, and Law: A Study Written for the Law Reform Commission of Canada*****, 224 pages, Law Reform Commission of Canada, 1979. Reproduced with the permission of the Minister of Public Works and Government Services Canada, 2011.**"

Law Reform Commission of Canada
Commission de réforme du droit du Canada

sanctity of life or quality of life

PROTECTION OF LIFE SERIES

STUDY PAPER

SANCTITY OF LIFE

or

QUALITY OF LIFE

in the context of ethics, medicine and law

Protection of Life Series

Une édition française de ce document
d'étude est disponible.
Son titre est:

LE CARACTÈRE SACRÉ DE LA VIE
OU
LA QUALITÉ DE LA VIE

© Minister of Supply and Services Canada 1979
Available by mail free of charge from
Law Reform Commission of Canada
130 Albert St., 7th Floor
Ottawa, Canada K1A 0L6
or
Suite 2180
Place du Canada
Montreal, Quebec
H3B 2N2

Catalogue No. J32-3/20
ISBN 0-662-10445-5

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 Keyserlingk, 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:

Secretary
Law Reform Commission of Canada
130 Albert Street
Ottawa, Ontario
K1A 0L6

Table of Contents

INTRODUCTION 1

PART I. THE SANCTITY OF LIFE PRINCIPLE 9

Chapter 1. Roots of the Concept 9

- A. The Roots in Theology 10
- B. The Roots in Experience and Intuition 14
- C. Conclusions: Some Agreements 17

Chapter 2. Meaning and Use of the Concept. The Options ... 19

- A. "Vitalism" — the (only) Valid Expression of the Sanctity of Life Principle? 19
- B. The Sanctity of Life Principle — False or Meaningless? 25
- C. The Sanctity of Life Principle — Fundamental and Meaningful? 30
- D. Conclusions: the Relevance for "Quality of Life" 47

PART II. THE QUALITY OF LIFE 49

Chapter 3. The Quality of Life and Death 49

- A. An Elusive Concept — Subjective or Objective? Absolute or Relative? Equal or Unequal? 50
- B. "Quality of Life" in Environmental and Medical Contexts. A Comparison 53
- C. Life: A Good in Itself? Death: How "Define" It? 60
- D. Death with Dignity 66
- E. Conclusions: Equal Lives and Objective Criteria 70

Chapter 4. Person as a Normative Concept 75

- A. The Difficulties: a "Permissive" or "Protective" Role? 77
- B. Relevance and Meanings of Person. The Options 80
- C. Conclusions: Respecting Persons and Determining Personhood 102

Chapter 5. Treating and Dying 107

A. "Ordinary Means", or "Reasonable Treatment"? 107
B. Euthanasia or "Allowing to Die with Care"? 118
C. Conclusions: Refusing Treatment and Causing Death 131

Chapter 6. Rights and Responsibility in Ethics, Law and Medicine 135

A. Utility of the Rights Model, the Law Model 135
B. The Inadequacy of the Rights Model, the Law Model 142
C. An Ethic of Responsibility 145
   1. A Comparison with an Ethic of Rights 145
   2. Its Relevance for Law Making and Health Care .. 148
D. The Notion of "Ideal Rights" 152
E. Conclusions: Rights, Responsibility and Quality of Life 154

PART III. SOME RECENT PUBLIC POLICY GUIDELINES AND PROPOSALS — HOW THEY MEASURE UP 157

Chapter 7. Hospital Guidelines for the Terminally Ill 159

Chapter 8. Courts and Incompetent Patients 163

Chapter 9. Seriously Defective Newborns 169

Chapter 10. Allocation of Scarce Resources 173

Chapter 11. Natural Death/Living Will Legislation 179

PART IV. CONCLUSIONS: SOME PRIORITIES FOR PUBLIC POLICY AND LAW 185

ENDNOTES 191

SELECTED BIBLIOGRAPHY 219

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.

Many others at the Commission made indispensable contributions at various stages and in various ways. High on this list is my Assistant-Coordinator, Betty Rosenberg. Her reactions and contributions to the analyses and proposals, as well as her continuing encouragement, were no less valuable than her proofreading skills. Charles Lalonde (Chief of Publications) demonstrated his usual combination of skill, speed, availability and long hours in preparing the text for publication. William Taylor (Assistant Chief of Publications) was equally hardworking and helpful. My thanks as well to those who spent long and hard hours doing the typing and word processing with great expertise and speed, especially Heather Kelly, Leona Polgar, Betty-Lou Graziadei and Dianne Rathwell.

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 Christianity[12] 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-Stevas, 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 vestigal 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 fœtus), 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 fœtus;
- 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, fœtal 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 fœtus 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 Johannas 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" (I 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-Stevas 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, eduction, 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 or 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 de 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 data[96] 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'."[110]

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 fœtus is not, or is not yet a person then it is concluded that medical care and protection can be withdrawn, the fœtus 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 fœtus 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 fœtus.

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 fœtus 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 Teillard 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 fœtus, 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 fœtal 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 fœtus, 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 fœtal 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 fœtus 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 fœtus 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 fœtuses 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 fœtus 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 fœtus, 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 fœtal 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 fœtus begins to *look like a human*, sometime about the 6-week period. Still another proposed moment is that of the *quickening* of the fœtus, when the mother first feels the fœtus moving. Others claim it is when the fœtus 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 fœtus, 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 fœtal 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 fœtus 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 fœtus, does not necessarily imply that the fœtus "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 fœtus 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 fœtus 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 fœtus only moves from potential person without rights to actual person with rights, when the anchor of moral prerogatives and rights becomes present in the fœtus' 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 fœtus 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 fœtal 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 fœtus 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 fœtus, 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