Treating Seriously Disabled Newborn Children - The Role of Bioethics in Formulating Decision-Making Policies in Interaction with Law and Medicine

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ABSTRACT

The goal of this work is to explore the role of theological bioethics in influencing the formulation of existing or proposed policies dealing with treatment decisions for seriously disabled newborns in our pluralist society. Part I of the paper attempts to determine as precisely as possible what bioethics is, particularly Judeo-Christian bioethics. After comparing the latter to the Hippocratic tradition and to secular bioethics, the distinctive characteristics and potential contribution of theological bioethics are identified. The policies then examined in Part II are: medical policies formulated by physicians, bioethical policies proposed by bioethicists and legal policies enunciated by court decisions and legal writers. In each case they are evaluated in the light of a number of specific ethical tests proposed as central to Judeo-Christian bioethics. The paper concludes that Judeo-Christian bioethics has not been particularly influential in our pluralist society. A final section proposes a model treatment policy.

RÉSUMÉ

Le présent travail a pour but d'analyser l'influence de la bioéthique théologique dans notre société pluraliste, sur la formulation de politiques actuelles ou proposées relatives aux décisions en matière de traitement des nouveaux-nés sérieusement handicapés. La première partie du document tente de déterminer le plus précisément possible ce qu'est la bioéthique, particulièrement la bioéthique judéo-chrétienne. Après avoir comparé cette dernière à la tradition hippocratique et à la bioéthique philosophique, l'auteur énonce les caractéristiques distinctives de la bioéthique théologique et analyse son apport potentiel. La deuxième partie examine ensuite les politiques médicales proposées par les médecins, celles relatives à la bioéthique et formulées par les bioéthiciens et enfin, les politiques juridiques énoncées par la jurisprudence et la doctrine. Dans chacun des cas, les politiques sont analysées à la lumière de nombreux tests propres à l'éthique et considérés comme essentiels à la bioéthique judéo-chrétienne. L'auteur arrive à la conclusion que la bioéthique judéo-chrétienne n'a pas eu d'influence particulière dans notre société pluraliste. La dernière section du document propose une politique modèle de traitement.

Claims for originality

Among the original contributions of this thesis, the most important is that of measuring the influence of theological bioethics on actual working policies and attitudes of pediatricians and courts in decisions to treat or not treat seriously handicapped newborns. To this point no in-depth evaluation of this kind has been attempted. Also original is the effort in the first half of the thesis to compare in some detail the major bioethical "traditions", Hippocratic, theological and philosophical, in order to identify what are proposed in the thesis as the unique preoccupations and principles of theological bioethics. Lastly, an original contribution to learning is made by the proposed decision-making policy in the last chapter, a policy which could serve as an interdisciplinary framework for decisions to treat or not treat the seriously handicapped newborn.

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INTRODUCTION

This thesis explores the actual and potential influence of theological bioethics regarding one of the most sensitive and complex issues in our times - that of decisions to treat or not treat seriously disabled newborns. More specifically, it examines that influence upon the treatment policies articulated by physicians, bioethicists and the law. "Policy" is defined in this thesis as: a relatively coherent, comprehensive and detailed set of normative criteria, and a specific decision-making procedure, designed to protect, promote and balance the legitimate rights and interests of the affected parties.

The subject of seriously disabled newborns was chosen largely because treatment decisions involving these infants raise a number of new, urgent and as yet unresolved conflicts of rights, principles and values. Since the outcome of selecting a seriously handicapped infant for non-treatment is usually certain death, the infant is arguably the party most affected by that decision. But the newborn's parents are also directly affected as well; if selected for non-treatment they will lose their child, but if it is treated and lives they may incur the life-long burden of that child's care, a burden some parents feel is beyond their ability.

Health services and society generally are also directly affected by that decision. Each seriously disabled child who is treated and survives makes an additional claim on available, time and finances.

Since the various rights and interests of these and other parties are in many respects different and even competing, the function of treatment policies or guidelines is to establish the normative criteria which should apply, with a view to reducing arbitrariness and injustice to a minimum. Whether or not such treatment policies give explicit attention to the moral dimension, they cannot escape moral choices and implications by the choices each policy makes, of the issues, of the rights and interests addressed and not addressed, of the manner in which those rights and interests are ranked and balanced, and (on the procedural level) which party or parties will make the decisions and by what procedural mechanisms.

The ethical quotient of treatment decisions is therefore large indeed, and can be broken down into a number of specific questions. Our answers to these questions will be transposed into ethical tests in the light of which, in Part II of the thesis, various specific policies will be evaluated.

What, for example, is the proper role and what should be the limits of medicine in the alleviation of suffering? Is it within the mandate of medicine to seek to eliminate all suffering even to the extent of killing those disabled newborns medicine cannot cure? Do physicians have a continuing obligation to care for those infants who cannot be cured? What role and meaning should be given to "quality of life" considerations, and are such considerations incompatible with the sanctity of life principle? Should quality of life focus only on the infant's medical condition or be expanded to include factors such as burdens on others or the availability of future health care and services? Is there a moral distinction between killing disabled infants and allowing them to die? Are the rights to treatment and life of retarded newborns weaker than those with only physical disabilities? How are the rights and interests of the various parties to be ranked and balanced? May the interests or wishes of other parties take precedence over the right to life of a disabled but salvageable infant, or over the right of a disabled child not to have excessive hardship inflicted upon him by needless treatment? Should the wishes of parents regarding treatment or non-treatment of their disabled child always be the primary treatment criterion? Do parents have a right to be fully informed of their infant's status and prospects, and to be involved in treatment decisions? What is the role of the State, both in protecting disabled infants whose lives or health are endangered and in the provision of needed health care and services?

Simply determining and evaluating the ethics of treatment policies is not in itself the primary goal of this thesis. It is simply a way, in our view the only way, to determine the answers to our fundamental question - what is the actual and the desirable role of bioethics - particularly theological bioethics - in contributing to these treatment policies? The examination of the policies themselves is only a vehicle by which bioethics itself is being examined and tested.

As such, a number of related sub-questions addressed to bioethics form the threads running through the thesis. One has to do with the apparent influence of the values, principles and priorities central to Judeo-Christian bioethics on the views and positions of physicians, bioethicists and courts. Another has to do with the variety of moral stances and priorities within theological bioethics. Does that variety contribute to diluting the contribution to policy-making of Judeo-Christian bioethics? Which branch, school or denomination, and which position or trend within those branches or denominations should be considered by policy makers to represent normative Judeo-Christian bioethics when they (in some cases) promote fundamentally incompatible positions? Still another question has to do with the role of bioethics in policy making given that it must share that stage with other parties and disciplines, especially medicine and law. Is theological bioethics and are theologians, sufficiently mature and open to make their contribution in an interdisciplinary manner in a pluralist context, on the one hand acknowledging the essential and distinctive contributions of secular/humanist bioethics, medicine and law towards policy making, striving for as much moral consensus and tolerance as possible, but on the other hand ensuring to the extent feasible that those policies respect and accommodate fundamental Judeo-Christian insights and commitments?

Precisely because bioethics comprises a number of branches and sub-branches, Part I of the thesis is devoted to determining with some precision and detail what bioethics is, and the distinctive nature and potential contribution of theological bioethics. Theological bioethics shares the stage with both secular (or philosophical) bioethics and the medical ethics of the Hippocratic tradition. Given the interdisciplinary and pluralist context of interest to us in this thesis, the nature and contribution of theological bioethics could not be determined in isolation from the ethics of both the Hippocratic tradition and philosophy. Therefore all three are examined and compared in some detail. Since theological or Judeo-Christian bioethics itself contains three branches - Jewish, Protestant and Roman Catholic - they too are each studied and compared as well. The object of this exercise in Part I is directly related to and preparatory to the goal of Part II, namely that of enabling us to establish the ethical priorities and positions which most arguably reflect the Judeo-Christian tradition and can therefore best serve as the normative tests applied to the policies examined in Part II. What those Judeo-Christian priorities and tests should be is not of course self-evident or undisputed. It will therefore be necessary to devote considerable space to the task of comparing traditions, approaches and positions, and to argue the case for those moral positions and tests proposed as normative in this thesis.

Part I will conclude that the unique and central contribution of theological bioethics is not so much a matter of content as that of a special outlook, motivation, commitment and seriousness. The serious Jew and Christian is motivated by unique experience and stories which expand and illuminate principles and duties which in themselves may not be at all unique to the Judeo-Christian tradition. Those stories both reinforce the morality shared with others, but also challenge the serious believer to go beyond what reason and humanism alone can oblige. In terms of specific convictions, we shall propose that the one most fundamental to this tradition is that of respect for life, particularly for the most disadvantaged of our brothers and sisters, in many cases the mentally handicapped. In terms of specific attitudes central to this tradition, we shall propose that one is the attitude of openness - ensuring that ethical positions are refined and continue to evolve in the light of new medical data, possibilities and challenges. Another is that of an awareness of finitude and sinfulness - remaining alert to the temptation to make decisions for others which are supposedly in their best interests but are in reality for our own benefit or convenience. Another such attitude arguably central to the mandate of theological bioethics is that of making its contribution to policy in a "participatory" rather than prophetic or imperialistic manner - seeking consensus where possible, yet arguing its case forcibly by sharing its insights about the human condition and human worth with others.

Whereas Part I attempts to capture the bioethical principles and commitments of the Judeo-Christian tradition without yet applying them specifically to the context of the seriously disabled newborn, Part II begins by further refining those positions and tests in the light of the disabled newborn context. Nine such tests are proposed: the sanctity of individual life (though not in the "vitalist" sense of that expression), the rejection of (active) euthanasia, the legitimacy of qualify of life considerations which focus on the infant's condition and benefit as opposed to the benefits and burdens of others, the continuing duty to provide care and comfort even after therapeutic treatment ends, the equal treatment of the mentally disabled and physically disabled infant, the limits to parental decision-making authority, the importance of attitudes of openness and caution, the need for fairness, toleration and interdisciplinarity, making the bioethical contribution in a participatory manner.

Having established those ethical tests, Chapter VII applies them to medical policies, that is those used or proposed by pediatricians. "Policies" in this chapter include both policies in the strict sense as defined above, and also in the wider sense, that is, the views and practices of pediatricians particularly as found in a number of recent surveys. The reason for including the latter within the scope of "policies" is that the views of the wide and representative body of pediatricians canvassed in these surveys undoubtedly influence and reflect actual practices. They provide a window to what pediatricians really think and do in this matter of treating newborns whatever the more official or formal policies describe.

As for the more formal and full blown policies, three pediatricians (Lorber, Freeman and Zachary) have been selected, each of whom represents and promotes a different approach in the making of decisions to treat or not. While in some respects the differences are matters of emphasis and orientation, in others they are substantial.

A number of conclusions will be drawn on the basis of the evaluation of the surveys and formal policies. Among them are the following: many pediatricians appear willing to subordinate a disabled but salvageable infant's right to life to the lesser interests of others, which makes somewhat questionable their commitment to the sanctity of individual life, while active euthanasia may only be rarely practiced in these cases in an overt and direct manner, many pediatricians would like it to be made legal, and some policies and practices arguably amount in effect to the killing of some seriously handicapped newborns by (for example) a combination of over-sedation and consequent inhibiting of an infant's demand for food; many pediatricians have a very pessimistic and subjective estimation of the "worthwhile" quality of life, especially as regards mentally retarded infants, and are therefore prepared to allow "social" quality of life factors (such as parental wishes and burdens) to be decisive; many pediatricians are prepared to exclude parents from involvement in the decision as to whether their infant should be saved or not; pediatricians tend to focus almost exclusively on the burdens upon a family which keeps and cares for a disabled child, giving little or no attention to the joy and happiness the infants can sometimes bring as well; there is relatively little attention paid to the provision of (aggressive) treatment for purposes other than life-saving, especially that of improving comfort and function for the time remaining; a continuing duty to provide care when therapy is no longer indicated does not appear to be a priority in many policies and practices, there is little scope given to inter-disciplinarity - implicit in many views and policies seems to be the assumption that these decisions and policies can be made and formulated by physicians alone, there is little awareness about the legal rights and duties involved and considerable hostility about the intrusiveness of law, and the discipline of ethics is seen by some as more or less irrelevant; while there is some evidence that religion influences physicians' attitudes in these decisions, cultural background may be a stronger influence than religious affiliation.

Chapter VIII analyses four bioethical policies by three theologians and one interdisciplinary group and applies to them as well our normative ethical tests. The treatment policies selected are all quite different, and each represents an important perspective and trend. Fletcher's influential approach and criteria articulate a liberal Protestant stance. Ramsey, also a Protestant, and equally influential, represents the most conservative of stances. McCormick is a Roman Catholic, and stands somewhere between the two. The fourth bioethical policy, that of the Sonoma conference, was selected because of the multidisciplinary character of the group which formulated it.

It will be concluded about Fletcher's treatment criteria that many of his substantive positions and his general orientation are seriously out of step with the priorities and positions of Judeo-Christian bioethics which this thesis proposes as normative. His case-by-case approach, his "indicators of personhood" criteria and his rejection of the sanctity of life principle in favour of a largely subjective, pessimistic and utilitarian notion of quality of life, in our view make this policy one which invites arbitrariness, gives up too easily on disabled infants, demands too little of society by way of care and compensation, and ultimately is a policy not likely to be protective and just towards the seriously disabled newborn. That is especially the case for those who are mentally handicapped. There is as well no evidence of interdisciplinarity in his approach - it is largely an endorsement of subjective decision-making by physicians; the contribution and role of law is largely ignored. As for the "participatory" role of his bioethical policy, it is difficult to distinguish his position and criteria from a purely humanistic or philosophical policy. His position adds little or nothing to a constructive dialogue between disciplines and approaches, nor does it provide any challenge to prevailing trends and values.

McCormick's policy is particularly relevant for his insistence upon the normative value of quality of life considerations, his rejection of a vitalist interpretation of the sanctity of life principle, his compelling argumentation that both sanctity of life and quality of life find support in the Judeo-Christian tradition, and his claim that to preserve a life beyond a certain point can be a violation of the sanctity of life principle. We will attempt to demonstrate that in most other respects as well his treatment policy is influenced by and based upon the Judeo-Christian ethical priorities serving as our norms. Against Fletcher and others he insists that man's dignity does not lie in his functional proficiency or his utility but in the love God has invested in him. He also insists upon the duty to go "beyond reason" in our efforts to compensate and protect the least advantaged infants. We will examine at length McCormick's proposal that "relational capacity" as a fundamental human characteristic should also be the major quality of life criterion in making these treatment decisions. In our view that proposal has some serious limitations - mainly the absence of appropriate diagnostic symptoms, in all but extreme cases, by which to determine its presence, absence or degree, and the resulting dangers such a criterion presents of arbitrariness and subjectivity.

As for Ramsey, we will give particular attention to his absolute rejection of quality of life considerations and his choice instead of a "medical indications" policy. Much in Ramsey's treatment policy reflects and supports the ethical criteria we propose as normative, especially his insistence upon the infant's benefit and condition as the decisive factors to the exclusion of the interests and wishes of others, as well as the emphasis he puts on the continuing duty to care (as opposed to treat) no matter what the infant's prospects. But we will not agree with him that quality of life factors should never influence treatment decisions and are inherently and inevitably threatening to the well-being of disabled infants. It will be argued that a policy based upon medical indications cannot reasonably exclude some quality of life implications from the calculation of whether or not treatment is indicated. As will be indicated, it depends of course upon the particular meaning and scope one gives to "quality of life".

The policy and the deliberations of the fourth set of criteria selected, that of the Sonoma conference, will allow us to draw some at least tentative conclusions about the possibilities, pitfalls and limitations of such interdisciplinary undertakings. Our question will be whether our normative Judeo-Christian priorities and commitments are respected and provided for or submerged in such a process and policy. Our conclusion will be that, at least in this instance, the theologians who contributed to it conceded too much. It will be demonstrated that instead of participating and challenging, theological bioethics in this case appears to have played a largely conciliatory role, too ready to accept the minimal or reductionist morality which emerged. Little is left or recognizable of Judeo-Christian insights about respect for life, human worth and the weaker members of society. The very generality, ambiguity and vagueness of many of that policy's elements justify a wide and contradictory range of interpretations as to what actions are being promoted and discouraged. Despite its shortcomings, however, we will not conclude that such interdisciplinary efforts are necessarily misplaced. Quite the contrary - it is imperative that they continue, but the theologian participants must define their role and message more sharply, and be more prepared to challenge conventional trends and morality.

Chapter IX deals explicitly with the position of the law regarding the treatment of the seriously disabled infant. Given the primarily bioethical focus of this thesis, the legal dimension, a major and difficult subject in itself, can and should only be dealt with in a summary fashion here. The legal perspective cannot, however, be left out entirely, given our insistence that these policies should be formulated in an interdisciplinary manner, with ethics, medicine and law each contributing what it legitimately can. As well, given the fact that society expresses its protection for the lives and health of its members in part at least by means of law, the determination of what is legal and illegal in these treatment decisions is obviously crucially important even in a paper concentrating on the ethical dimension.

Largely by the examination of specific court decisions, this chapter will deal with only three of the normative priorities or tests central to this thesis, by summarizing the legal stance on euthanasia, allowing to die/quality of life, and parental decision-making authority. Our general question in each case will be the extent to which the law reflects the ethical stances we have proposed as normative. It will be concluded that about all three issues there is a striking concordance between the legal and bioethical stances. The law prohibits the killing of even a very seriously disabled newborn by act or omission, and even though the motive is that of compassion. In the eyes of the law a disabled newborn is a person with full rights to all relevant legal protections. That does not however mean the law prohibits allowing an infant to die when further treatment is judged useless. The quality of an infant's life can be a legitimate consideration in such cases. As for parental authority, the law considers parents to be trustees over children, not their owners. As such their decision-making authority is limited to decisions which do not threaten their childrens' life, health or best interests.

In the last chapter, Chapter X, we will draw some conclusions about the role of bioethics in these treatment policies in the light of the preceding chapters and analyses. The general conclusion will be that the policies and views considered indicate that some orientations and positions central to Judeo-Christian perceptions and commitments presently play only a minor role in decision-making policies and criteria relevant to the seriously handicapped infant. Other and contrary considerations often appear to predominate. As a concrete means of drawing together the claims and conclusions of the thesis we will end by proposing a "model interdisciplinary policy" in the form of eighteen propositions, each followed by a brief comment. This model policy is by no means proposed as a comprehensive set of criteria able to stand on its own without expansion and refinement. Our claim for it is far more modest, namely that its propositions arguably articulate the priorities central to Judeo-Christian ethics regarding handicapped infants, but also that they would by and large be acceptable to at least some versions of secular/humanistic bioethics, and that they are within the bounds of the law.

PART ONE. THE MEANING, VARIETIES AND PRIORITIES OF BIOETHICS

Chapter I. Bioethics - its nature and challenges

1. The challenge to bioethics - the ethical quotient of newborn treatment decisions

As Chapter VII of this thesis will demonstrate in some detail, decisions by physicians to withhold medical treatment of disabled newborns are made in practice for a variety of reasons and those reasons are assigned different weights and interpretations by different physicians, neonatal teams or institutions. It has long been known that the medical anomalies alone of disabled newborns are not the direct or single causes of all neonatal deaths. While in most cases imminent death is inevitable, in many other cases death is at least associated with decision-making by physicians and third parties, especially parents. Already in the early seventies a survey done in one hospital over a two year period concluded that fourteen percent of the neonatal deaths in that special care nursery were linked to the refusal, withholding, discontinuance or withdrawal of treatment.[1]

The reasons given for withholding treatment are various, but generally related to the "quality" of the newborn child's life. But "quality of life" is anything but a definite, univocal and completely scientific criterion. The degree of health or quality needed in a disabled newborn in order to trigger needed treatment, is itself subject to a number of considerations and criteria. On the one hand surveys and interviews establish certain patterns and similarities in those quality of life considerations and treatment conclusions. But on the other hand, even allowing for the fact that no two medical anomalies in disabled newborns are exactly alike, the evidence suggests a fairly wide latitude as to what constitutes an "acceptable" (for treatment) quality of life, and the factors which legitimate that decision.

A major factor in the physicians' judgment is the estimation and decision of the child's parents regarding their own child. When informed of the diagnosis and prognosis, parental decisions and wishes are often made the decisive yardstick of a quality of life which is or is not worth treating.[2] But some physicians and institutions tend to treat or not more or less irrespective of parental wishes, determining the quality of life acceptable for treatment exclusively on medical grounds.[3]

A striking example of the latitude in treatment decisions is evidenced for example in the very different policies applied by Doctors John Freeman in Baltimore, Maryland,

and John Lorber, in Sheffield, England regarding children born with spina bifida. Dr. Lorber treats only twenty-five percent of the disabled children brought to him, whereas Dr. Freeman treats ninety percent. That means in effect that a child brought to the Childrens' Hospital in Sheffield will probably go untreated and will die, whereas one brought to the Johns Hopkins Hospital in Baltimore will probably be treated and will survive.[4] That in turn suggests that whether these children live or die will be determined to a large degree by the accidents of their place of birth and the institution to which they are referred.

On studying their respective statistics and explanations it becomes clear that the radical difference in these selective non-treatment policies is only partially explained by the quite different estimates on medical grounds as to what the future impairments or quality of life of those children will be, Dr. Freeman being considerably more optimistic than Dr. Lorber. It is also that they disagree as to what is or will be for those children an acceptable quality of life. In this they reflect an on-going and seriously troublesome debate in the medical profession everywhere.

The quality of life net tends to include within it considerations well beyond parental definitions and desires or medical prognoses as to future impairments. As will be demonstrated in Chapter VII, the quality of life of the <u>child's family</u> is sometimes as determinative of treatment or non-treatment as the quality of the child's life in the strict medical sense. Surveys and interviews indicate that a seriously disabled child born to a young, unwed, single mother, or to parents who appear to have psychological or economic problems, or to a family in which the other children may react adversely, or to a family which does not seem to want the child, are less likely to be treated than those children born to families where these conditions do not apply.[5]

A significant feature of selective non-treatment decisions is the influence of mental retardation. Some surveys and interviews indicate that the presence of even mild mental retardation is far more likely to lead to non-treatment than are relatively serious physical handicaps without evidence of retardation.[6] Retardation appears to evoke in both physicians and parents considerably more discomfort and pessimism than do physical handicaps, and to be subject to different treatment criteria.

Still another criterion sometimes associated with quality of life and prognosis is that based upon the allocation of (scarce or expensive) resources. In such a case treatment of one disabled newborn is withheld or discontinued because another newborn has a better prognosis. This criterion especially applies, it is argued, when there are limited medical resources available and both babies cannot be saved.[7]

A further and related quality of life criterion for selective non-treatment sometimes advocated is that of the burden and expense on society should seriously disabled children requiring life-long medical treatment and other forms of support be treated and survive. Some decisions to treat disabled newborns, it is argued, impose unfair burdens and expenses on society, depriving those better able to develop and contribute from the services and benefits otherwise available to them in larger quantities.[8]

A last quality of life position worthy of brief mention at this point is the view which advocates not just the discontinuation or non-initiation of treatment, but the active killing of those newborns selected for non-treatment. Surveys and interviews indicate that this view is shared by only a very small minority of physicians and parents, but directly or indirectly it is not without its proponents. For example, Dr. John Freeman asks about those children selected for non-treatment:

> If it is best for these children to die quickly, why not help them? Would that not be more humane? ... Protection can be built into a euthanasia process, but at present we have no protection against the physicians who select a group of individuals to die.[9]

At a 1974 interdisciplinary conference (including pediatricians) at Sonoma, California on neonatal intensive care, seventeen of the twenty participants answered yes to the following question: "Would it ever be right to intervene directly to kill a self-sustaining infant?" We are told that many (especially the physicians) would not themselves do so, but would not condemn others who did. Some others who answered in the affirmative confessed to remaining "emotionally uncomfortable" with such a course of action, though intellectually in agreement.[10]

The above is only a summary of medical attitudes and practices which will be documented and evaluated in some detail in Chapter II. The purpose of this summary at this point is only to reinforce what is more or less self-evident - that there is a very large quotient of ethical content in decisions for or against the treatment of seriously disabled newborns. Whether they live or die in practice unavoidably depends not only on the nature and seriousness of the mental and physical anomalies in the strictly medical sense. It also depends upon the value judgments of various parties, usually the physicians and parents, sometimes the courts as well, as to what constitutes a life worth living.

Implicit in the various quality of life criteria factors just listed are a number of fundamental ethical questions and dilemmas which will preoccupy us throughout this thesis. As we shall have occasion to establish later, they often tend to be answered differently by the various parties involved (medical teams, parents, courts and legislatures), and by the two main streams of bioethics (religious and philosophical), and by the various branches or "schools" within those two streams. As we shall attempt to demonstrate, it is partly that pluralism in practice, tradition and method which on the one hand makes the formulation of policies and guidelines so necessary (to establish basic standards and protections), and yet on the other hand makes substantive (as opposed to procedural) policies so difficult. The gulf between the interests and priorities of the relevant parties is not easily narrowed, and consensus between various ethical traditions and approaches is not readily achieved.

In general and summary terms then, what are the major ethical questions which will preoccupy us? A first and fundamental one is that of the proper role and limits of medicine in treatment decisions for disabled newborns. Given advances in neonatology, many disabled babies who would have died soon after birth can now be saved and restored to health. But some can only have their lives prolonged - the severe handicaps cannot be corrected. For <u>some</u> of these babies medicine can probably do <u>too much</u>. It may for instance be beyond the role and mandate of medicine to routinely and aggressively treat all disabled newborns, even to the point of merely prolonging the dying process and suffering of babies who cannot be restored to any significant level of health. Such a policy might result in technological successes, but medical and ethical failures.

But it is equally possible that humanitarian infanticide also oversteps the limits and mandate of medicine. Those (few) physicians and parents who advocate humanitarian infanticide for those seriously disabled newborns who cannot be cured, are in effect implying that it is the role and obligation of medicine to eliminate suffering, to deliver happiness in all cases, even if it means killing when curing is not possible. But such a premise and policy require serious ethical examination. Medicine is not necessarily responsible for eliminating all suffering (even if that were possible), and there are some limits to be established to medical intervention in the lives of newborns.

Still on this point, it is possible for medicine to do too little, and not just too much for disabled newborns. A decision for non-treatment could be arrived at too quickly. The future quality of a child's life could be judged too pessimistically. A child selected for non-treatment could be allowed to die without continuing efforts to provide comfort and care.

The challenge to bioethics regarding the role and limits of medicine in these cases is of course greater than the mere formulation of these general principles. What remains is to examine each of them, to balance them, to test them in concrete cases and to provide moral reasons for the balances and particulars advocated. If medicine should not treat <u>every</u> seriously disabled child, then which ones, and on what moral grounds? If medicine should treat those with lives worth living, then what is a "life worth living" when that evaluation cannot be made by the disabled child itself? And if physicians should not kill seriously disabled newborns, in which moral arguments should that prohibition be anchored?

A second and related ethical issue of concern throughout this paper is that of "quality of life". Given that variations on this theme play such a large role in medical and parental decision-making, the notion must be subjected to rigorous ethical scrutiny.

Do quality of life considerations implicitly and necessarily threaten respect for the sanctity and equality of all lives? Is the notion altogether too elastic, relative and subjective to be applied in policies and guidelines with any consistency and objectivity? What special moral considerations are involved when one's present and prospective quality of life is judged by another, as in the case of disabled newborns being considered for non-treatment? What should be the standard of what will count for another as a life worth living, and what properties should be sufficient to achieve that standard? Is life a relative good, a condition of other goods and values, or a good-in-itself, to be preserved at all costs? What significance should estimates of pain or unhappiness or intelligence have in determining the quality of life of a disabled newborn? What significance should mental retardation have in estimating the quality of that life? Should quality of life evaluations for treatment decisions be confined to strictly medical diagnoses and prognoses, or be expanded to include factors such as the marital, economic or psychological status of the child's family, or the financial and other burdens to society if treatment is initiated?

Are some decisions for non-treatment based on quality of life prognoses too inattentive to the potential in some disabled newborns to overcome handicaps ~~and~~ develop potentialities if provided with proper care and resources? Do some decisions not to treat in view of the projected quality of life demonstrate a too complacent acceptance of the status quo in terms of available services and resources to assist these children in achieving the maximum development of their potential?

All of the above are fundamentally ethical questions, at least some of the answers to which will differ depending upon the values and principles of the individuals or traditions responding. Obviously for example if one holds that life as an intrinsically valuable good in itself, created by God and to be supported no matter what the disability, then quality of life criteria will tend to be rejected as morally incompatible with that religious conviction. Just as obviously, if one holds, on the basis of rational ethical reflection that only those with a capacity for a certain level of intelligence are truly human and deserving of support, mentally retarded newborns will tend to fall outside the category of humans and will be likely candidates for non-treatment.

A third ethical issue is that of whether there is a moral distinction between killing disabled newborns and allowing them to die. As already noted, it is sometimes maintained that the decision not to treat is already to intend the death of that child. That being so, it is argued, it is more compassionate to actively kill that child than to simply let it linger on becoming progressively more disabled. It could be argued that in some instances and institutions the aftermath of selective non-treatment decisions in effect involves not so much "allowing" those children to die as much as "pushing" them to death. That may well be the case when babies selected for non-treatment are kept so sedated that they do not demand food and die within the first week.[11]

Quite obviously, treatment policies and practices which assume no significant moral difference between killing and allowing to die, can be expected to produce radically different results for children than policies and practices which do assume a moral distinction. A treatise such as this one, evaluating the role of bioethics in the formulation of these policies, must therefore determine and weigh the various moral arguments pro and con on this most ethical of issues, and the influence of those moral arguments on existing and proposed policies. It will especially involve consideration of notions such as duty, intention and the sanctity of life. Not surprisingly we will find that on this ethical issue more than any other there is a marked difference between the convictions and conclusions of religious ethics and secular ethics, and in the policies more dependent on one "tradition" than the other.

A fourth ethical concern is one already referred to in the context of other issues, but is important enough to merit separate attention - briefly at this point and in detail at various points below. The issue is that of the retarded newborn. It is an ethical issue because more than any other handicap the presence of mental retardation challenges us to articulate a conception of normalcy and the "normatively human", and to determine our obligations accordingly.

Some ethical analyses and treatment policies perceive the issue as essentially a choice between the rights of the "normal" and the rights of the "retarded", choosing to promote a healthier world with fewer burdens on those who already exist, by letting the seriously retarded newborn die. The motive is humanitarian - a better world is the goal, achieved by sacrificing the few for the many. A contrary ethical stance argues that a "better" world bought at that price cannot really be better, that society and its individual members have a duty, for some a duty founded on Judeo-Christian obligations, to care for and improve the lot of the retarded, the weakest and most vulnerable members of the human community. That view tends not to be impressed with visions of a better world or the interests of society as a whole, and is willing to stand against the trend to exclude the mentally retarded from full personhood and access to the same protections and resources as those who are "normal".

As we shall indicate below, on this issue as others religious ethics and secular ethics tend to part company, as do the treatment policies more influenced by one or the other ethical tradition.

There is yet a fifth ethical problem of interest in our inquiry, one which is both procedural and substantive in nature. It is the very thorny one of determining and ranking the interests of the various parties involved in and affected by treatment decisions for disabled newborns, and ensuring in relevant policies that those interests will be provided for and respected. It is a procedural issue insofar as the "who decides" question and appropriate decision-making mechanisms are addressed, but at a prior and more fundamental level it is also an issue of substantive ethics in that it must first of all be decided, on sound moral grounds, what those interests are and how they are to be balanced.

The first and most important party is obviously the newborn child himself or herself. But since newborns cannot express their own interests and choices, they will always need others to interpret and provide for their presumed interests. It follows that determining and protecting their interests will inescapably depend upon the values and preference of other parties, upon what those others think they themselves would want done or not if in that child's position, how those others perceive their moral obligations to that child. While no one can ever put oneself in another's shoes without some degree or risk of subjectivity and self-interest, the interests of the child in question would seem to demand that every effort be made to identify and ethically ground the disabled child's interests with as much objectivity as possible, and to carefully articulate them in treatment policies. Focusing on the interests and benefits of the child does not of course rule out of order consideration of and balancing with the interests of other parties. But since it is the life of that child at issue, lesser interests of others will be secondary.

As we will indicate in detail in the course of this thesis, there is considerable variety in bioethical stances on the matter of the interests of the seriously disabled child. For example, for some ethical analyses, the primary interest of the child is the saving and prolonging of its life, even in the presence of serious handicaps. From this perspective the interests of the child in surviving would admit of very few exceptions permitting non-treatment. Another ethical stance would see the primary interest of the child as one of living with a "minimum" of pain and suffering. If the prognosis indicates this will not be possible, then non-treatment and early death is the appropriate response. A third ethical position sees the primary interest of the disabled child as that of maximizing its potential despite handicaps by having available throughout its life needed care and resources. These three and other positions are not necessarily of course mutually exclusive, but they do represent different emphases and do tend to promote different outcomes as to whether the child in question will live or die.

A second party is that of the parents. They have important interests and responsibilities, both because it is their child at issue, and because they will have duties and burdens in caring for their child if treatment is initiated or continued. They therefore have an interest in speaking for the child. In most cases involving decisions to treat or not, ethical analyses and policy formulations acknowledge that parents should indeed be the primary decision-makers, and the primary interpreters of the best interests of their child. The cases for which there is near unanimity in ethical analyses are the unsalvageable cases, those in which the child faces impending death and for whom no medical intervention would help even when the social conditions are perfect.

But there remain a number of situations in which the role and interests of the parents are less than clear and about which various ethical analyses and policy formulations differ. For example, may parents refuse life-saving treatment for their disabled newborn child in virtue of their own emotional or financial inability to provide needed care and other resources for a child diagnosed to be medically salvageable? Are physicians morally bound to respect such wishes or to refuse them? Another example: if parents are the primary decision-makers, then it follows that they have an interest in being given all the information necessary to make a free and informed decision about their child. But what if the medical staff judges that they are emotionally too distraught to handle the disturbing information or to make a decision, and therefore withholds the facts and reserves the decision for itself?

That brings us to the third party with interests and responsibilities in this matter, the medical staff. A primary interest and duty of the medical staff is that of providing the best possible medicine and care for the disabled child, but also to care for and support the child's parents and family. Therein lie the seeds for one of the ethical problems - who is the physician's patient, the child or the parents, or both in different degrees? If the parents wish a course of action (whether treatment or non-treatment) judged by the medical team to be against the best interests of the child, should the parents' wish nevertheless be respected? Some medical policies would answer in the affirmative, some in the negative. An example of an affirmative answer is the position of the Judicial Council of the American Medical Association which maintains that:

> In desperate situations involving newborns, the advice and judgment of the physician should be readily available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents.[12]

It could be asked whether that position is sufficiently reflective of the distinct possibility that parents may be (albeit unconsciously) confusing their own interests for those of the child. But on the other hand, are physicians competent and morally entitled to make that judgment and act against the parents wishes, especially when there is a degree of uncertainty in the medical prognosis?

There is yet a fourth party with interests and duties in treatment decisions for disabled newborns, namely the State. In general terms it expresses those interests and duties in two forms - by the provision and fair distribution of child services and resources, including to the least advantaged, and by means of legal protections and interventions by exception when called for. But within those general interests and duties of the State lie a number of complex and unresolved problems and balances, all of them to some degree ethical in nature.

As regards legal protections and interventions in these issues, common law tries with some difficulty and little predictability to reconcile two not entirely compatible doctrines. One is the recognition and presumption in law (though rebuttable) that parents are the appropriate decision-makers for their children, including when it comes to making treatment decisions for them. But at the same time the State's parens patriae power can be exercised to intervene on behalf of children alleged to be victims of or threatened by abuse or neglect by parents or others. This intervention can take the form of punishment after the event, or a court may intervene before a decision or act by making a needed decision itself to ensure that a child will not be treated against its interests. The latter happens by exception when a physician and parents do not agree concerning a seriously disabled child's treatment, usually with the aid of a court appointed guardian. But when the somewhat general notions of abuse and neglect are applied to the particulars of a given case involving selective non-treatment, courts are not all in agreement as to the facts and principles which should be given the most weight. As we shall note at a later stage of this paper, courts will often directly or indirectly seek assistance, in resolving these conflicts by weighing various ethical views and arguments. In this we find one of many practical instances in which law and ethics are by no means distinct and separate in their goals and methods.

The other main expression of the State's interests and obligations is that of the provision of adequate services and resources to all members of society. Here too there are important and urgent ethical choices to be made. Some would argue, that health resources and care should be distributed fairly to <u>all</u> members of society, including to the most disadvantaged such as seriously disabled newborns, and that where they are not adequately available they should be increased. The grounds for this position could be the general ones of fairness and equality, or (for example) the more specific one that if the State determines that a salvageable newborn should be treated against the wishes of parents unable or unwilling to provide adequate care, then the State itself has the duty to provide that care.

Against this it is argued by others that there are limits to the resources of the State and therefore to available health services, and to provide more of them to care for newborns who will continue throughout their lives to require a major drain on health resources will mean the provision of less care to other groups also in need. The limited resources argument does not necessarily of course defeat ethical pleas for the provision of increased services for disabled newborns and children - it may simply point to the need for the State to work out more explicit allocation policies and priorities than presently exist. It is difficult to think of another exercise with a higher quotient of ethics than that.

A sixth and last ethical issue brings us to the heart and goal of this thesis, namely the present and desirable role and contribution of <u>bioethics itself</u>, particularly that of religious bioethics, in formulating treatment policies for disabled newborns. That will be the theme question running through all the issues considered. Clarifying those related and subsidiary issues will gradually provide the shape of the actual and arguable role of bioethics in these treatment policies.

Given that our primary interest is in <u>religious</u> bioethics, there are three important questions to be considered within our larger one. The first arises inescapably given the nature of our pluralist society. It has to do with the possible and desirable degree of consensus on this issue. Put simply, the question is this: can there be a policy consensus without a consensus at the level of belief, of conviction? Implicit in that question is a further one - how much consensus is necessary at the level of belief if resulting policies are not to remain too general or exclusively procedural?

A second issue is that of the relationship and distinctions between religious bioethics and secular or philosophical bioethics. Since both branches have positions on the treatment of newborns, and both contribute to policy formulations, it is of course impossible to treat the role and stance of religious bioethics in this area without attempting to identify the differences and similarities in their roles, foundations and conclusions. As we shall have occasion to note, there are some indications suggesting few significant differences in the way religious bioethics concludes about this problem compared to the positions of secular ethics. But there are other indications that there are in fact some significant variations at least in emphasis and motivation.

A third issue within our focus on bioethics is that of its relationship to the legal aspects of newborn treatment policies. It is of course true that law and bioethics are distinct entities and should not be confused one with the other. But law has in fact expressed positions on many of the ethical points indicated above in the form of court decisions, legislation and legally endorsed guidelines. The law has for instance made it quite clear that humanitarian infanticide is presently illegal, that non-treatment of newborns is sometimes legal, that there are some legal difficulties with the notion of quality of life, that newborns should not be abused or neglected, and so forth.

There are at least two ways in which that body of law is related to ethics. It is first of all the fact that it contains so much ethics. It could hardly be otherwise given the nature of the issues addressed and the fact that (good) law both provides access to the morality of earlier times by its commitment to precedents, and refines it by reflecting the morality of our own times. That point is sometimes acknowledged by ethicists. Paul Ramsey for instance put it this way in the preface to one of his books:

> I mean also to hold up these legal processes and the law's final authorization of important policies as mirrors in which we can see reflected the state of moral

> questions as these are perceived today - mirrors in which powerful trends in the ethos of contemporary society can be clearly seen.[13]

Ramsey made the same observation in another of his works when he wrote that:

> ... in the fabric of the law we have a depository of ethical decision-making, a civil tradition from the past until now, in which we can see morality "writ large", a continuity of moral judgments developed over time and honed in the prism of case after case.[14]

Another way in which ethics is related to law follows from the above. Precisely because of the high content of morality in that body of law, it is an urgent and natural part of the role of ethics to subject those decisions and that legislation to critical analysis. This position as well was endorsed by Ramsey when he noted on the subject of legal decisions, "Ethics is, among other things, the critical study of the grounds and validity of those decisions".[15] It would be a mistake to assume that <u>all</u> legal positions on our issues are beyond ethical criticism. One should not uncritically identify the legal with the ethical, or the illegal with the unethical. It is after all possible that some legal positions and judgments on our issues do not in fact reflect contemporary morality, or have failed to provide convincing moral arguments, or have overlooked an important moral feature of the issue.

2. Bioethics - some ingredients and dangers

The next task is to separate and study the various strands which make up bioethics. Our purpose in doing so is twofold. First of all to determine what bioethics is, particularly religious or theological bioethics, and what it could be expected to contribute to the formulation of treatment policy regarding newborns. If, as we intend, those policies are to be subjected in this paper to bioethical criticism, then a prior task is obviously to determine the shape and health of that ethical discipline itself.

But bioethics itself is not at all accurately referred to as "it". A more precise description or analogy would be that of a cloth with many strands, or a symphony with some basic themes but many variations. At least in a general and summary manner it is important for our task to understand the differences in colour and texture of those strands and variations. That is especially so given that our primary interest is in religious or theological bioethics. It shares much with secular or philosophical bioethics, to the point that their respective strands are far from easy to separate, and in many ethical analyses and polices they are assumed to be more or less the same thing. Yet according to some there are major differences, at least in emphasis. It will be a goal of this chapter to compare religious and secular bioethics and come to a conclusion as to how if at all they are distinct in their methods and concerns. That done, this chapter will conclude by proposing a way in which the two can and should interact in a single policy devised for our pluralistic society, a form of dynamic co-existence which would be faithful to the distinctive yet related concerns of each tradition.

The similarities, differences and interaction between religious and secular bioethics will be addressed in this chapter only in a general manner with few references to the specifics of the treatment of disabled newborns. But the purpose is to provide a foundation on which to place and justify the application of those findings and proposals to the specifics of the discrete issue of the selective non-treatment of newborns. That next task will occupy Chapters II and III of this thesis.

A. Bioethics as a discipline - a profile

But lest the exercise of separating the strands of bioethics in what follows imply that these traditions have little or nothing in common, or that these traditions are not subject to similar limitations and pitfalls, we will venture already at this stage some general and very summary characteristics and problems with bioethics which apply to both religious and secular branches.

A general definition of bioethics or medical ethics which would fit both branches is one provided by Paul Ramsey:

> Normative medical ethics, then, means the application of evaluative norms of some sort in appraisal of practices in medicine. In terms of "is-ought", we would be trying, as the outcome of ethical discourse, to tell what ought not to be that may now be done, or what ought to be that is now not done.[16]

But is bioethics a "discipline" in the strict sense, restricted only to trained theologians or philosophers and intellectual inquiry to the exclusion of for example belief, tradition and attitudes? A brief answer to this question or these questions will point to some limitations and remaining challenges in bioethics.

As to whether medical ethics or bioethics is a discipline, the safest answer is that it is, but a discipline (or sub-discipline) still "in evolution". On the one hand its principles and methods come largely from moral theology or moral philosophy, the difference or addition being that these principles and methods are now focused on medical and biological issues, some of these issues having been with us for some time, but most of them quite new at least in their various complexities.

But on the other hand there is an unfinished, evolving and unsettled quality to bioethics as a discipline, in large part due to the many and quite different subjects falling within its purview, the many fields which contribute to it and the quite different starting and therefore finishing points of those who practice bioethics. There is a continuing search for appropriate foundations and theories for bioethics, ones which could apply in a pluralist setting. That search is generally more the case in the secular branch of bioethics than in the theological, though certainly true of both. One view of the unfinished, unsettled nature of medical ethics was this one by Jonsen and Hellegers in 1974:

> Medical ethics is currently in a muddle. Many questions are asked, but few answers are offered. Many anxieties are aired but few are assuaged. Worst of all, the diversity of subjects discussed and the variety of arguments propounded makes one wonder whether there is any proper subject matter or proper methodology deserving the name, "medical ethics".[17]

Another bioethicist, Daniel Callahan, however, did not necessarily deny some two years later that bioethics was in a "muddle", but he was considerably more optimistic about the significance of the new and evolving nature of bioethics as a discipline. He saw hope and opportunity precisely in its lack of determined parameters:

> Bioethics is not yet a full discipline. Most of its practitioners have wandered into the field from somewhere else, more or less inventing it as they go. Its vague and problematic status in philosophy and theology is matched by its shaky standing in the life sciences. The lack of general acceptance, disciplinary standards, criteria of excellence and clear pedagogical and evaluative norms provides, however, some unparaleled opportunities. It is a discipline not yet burdened by encrusted traditions and domineering figures. Its saving grace is that it is not yet a genuine discipline as that concept is usually understood in the academic and scientific communities. One has always to explain oneself, and that leaves room for creativity and constant redefinition, there are many advantages in being a moving traget.[18]

Looking back at that assessment of bioethics eight years later, it is arguable that in the intervening years bioethics has in many respects matured considerably as a discipline. For one thing, its "shaky standing" in the life sciences has become more secure. For example, bioethicists, both philosophers and theologians are now regular participants in national policy committees (on death and dying, fetal research and many other issues) and hospital ethics committees, both Canada and the United States have a number of national institutes of bioethics and the number and quality of published works in bioethics and medical ethics journals has greatly increased, formal courses in bioethics are now on the curriculum in many medical schools, and bioethics has proven to other disciplines that interdisciplinary scholarship is both realizable and productive.

Nevertheless, a number of the temptations and limitations in the practice of bioethics which were signalled by Callahan and others some years ago remain such today. Some of them may in fact arise because bioethics has tended to become too much a discipline, a discipline too much like others in academe. Its biggest and constant difficulty is that of being meaningful and of practical help to those who have to make hard ethical decisions with little or no time for profound and lengthy theological or philosophical discussion, medical teams for example. It can hardly be denied that the ultimate purpose and test of bioethics is not that of a continuing and interesting discussion in an academic setting, but to aid those who must make decisions "on a given day at a given hour".

B. Disciplinary reductionism, excessive intellectualism

Without in any way denying the validity and necessity of bioethics and bioethicists attending with rigour and depth to the intellectual clarifying of ethical concepts, issues and language, that will not be sufficient. To be meaningful and helpful in actual decisions and policy formulation there are arguably at least three further and related requirements. One is to confront the issue in question with all the complexities with which it comes, resisting the temptation to what Callahan calls, "disciplinary reductionism". Another is to avoid the temptation to restrict the methodology of bioethics only to intellectual inquiry to the exclusion of other factors which influence good ethical positions and decisions, for example, experience, emotions and beliefs. A third requirement is the need for bioethics to be and remain interdisciplinary in nature.

The tendency to "disciplinary reductionism" was rightly noted and well expressed by Callahan:

> ... the ethical issues of medicine and biology rarely present themselves in a way nicely designed to fit the kinds of categories and processes of thought which philosophers and theologians feel secure about... The issues come, that is, in a messy, jumbled form, cutting through many disciplines, gumming up all our clean theoretical engines, festooned with odd streamers and complicated knots. The fact that this is the case immediately invites the temptation of what can be called, "disciplinary reductionism". By that I mean a penchant for distilling out of an essentially complex ethical problem one transcendent issue which is promptly labelled _the_ issue. Not coincidentally, this issue usually turns out to be a classic, familiar argument in philosophy or theology. By means of this kind of reductionism, the philosopher or theologian is thus enabled to do what he has been trained to do, deal with those classic disputes in a language and a way he is comfortable with - in a way which allows him to feel he is a good "professional".[19]

The experience of many bioethicists who work in clinical settings indicates that this remains a temptation, perhaps the major barrier to interdisciplinary work and the provision of ethical assistance in a form useful to the medical decision-makers. Once complex, multi-dimensional problems are thus reduced, sanitized and re-cast in what a medical team considers arcane language and concepts, it is no longer the problem that team brought to the bioethicist and the ethical "solution" as well as the whole enterprise of bioethics can be easily dismissed as more or less uninformed and irrelevant. As we shall note at various points in this thesis, there are indeed instances of "disciplinary reductionism" in some policies and policy proposals directed to treatment decisions for disabled newborns.

It should, however, be observed as well, that "disciplinary reductionism" is hardly a problem or temptation unique to the bioethics among the disciplines. When it comes to making available to the non-initiate the insights and solutions of the parent disciplines to bioethics, philosophy and theology, those who practice those disciplines are not known for talking about moral problems in the language and manner of most people. But what of course makes it particularly incumbent upon bioethics to speak plainly and respond to problems without dismissing their annoying complexities and complications, is that bioethics possibly more than any other discipline or branch of ethics, is forced by definition to grapple with urgent and painful issues one or more of which will be faced by most people.

Many of them are life or death matters, as is the one being addressed in this thesis. In the context of the issues composing the object of bioethics then, reductionism, evasion and irrelevancy are clearly bigger dangers and evils than they might be for example in a philosophy lecture to philosophers on the relative merits of deontology over utilitarianism, or in a theology lecture to theology students comparing normative ethics to situation ethics.

The second tendency indicated above as equally to be avoided is that of limiting bioethics more or less exclusively to intellectual considerations. In discussing the differences between religious and secular bioethics at a later point in this chapter we will have occasion to consider this point in more detail, but it should be mentioned briefly at this point. Traditionally ethics has focused on thinking as regards methodology, especially philosophical ethics. Intellectual rigour and clarity in probing and analyzing terms, theories, concepts and language with logic and consistency of course remain important in bioethics as they are in philosophy and theology generally, but is that enough for bioethics? Do not factors such as feelings, convictions and behaviour merit serious attention as well? Ramsey for one appears at first sight to think that the intellectual dimension should continue to be the essence of what medical ethics is about when he writes:

> Ethics is not a matter of concerns or passion (praiseworthy as these may be in moral agents); it is rather an intellectual inquiry. Therefore education in medical ethics must necessarily be primarily literate.[20]

But it is clear from the wider context of Ramsey's thought, both in that source and elsewhere that he does indeed assign importance to factors beyond the strictly rational and intellectual. It is not so much that thinking itself is the essence and goal of bioethics, but rather that other means of arriving at or justifying ethical decisions, such as experience, belief, tradition, behaviour, feeling, training and so forth should be <u>thought about</u>, subjected to a framework of analysis, not simply accepted or continued uncritically.

But neither should these considerations be disqualified as important elements in how most people very often come to (good or bad) ethical decisions, just because there are some logical fallacies or inconsistencies according to one or another ethical theory. In this we agree with the following observation by Callahan:

> If ethics were nothing other than seeing to it that no logical fallacies were committed in the process of ethical argumentation, it would hardly be worthy of anyone's attention. It is the premises of ethical arguments, the visions behind ethical systems, the feelings which fuel ethical (or nonethical) behaviour, which make the real difference for human life.

> Verbal formulations and arguments are only the tip of the iceberg. An ethicist can restrict himself to that tip; he will be on safe enough professional grounds if he does so. But I see no reason why he can't dare more than that, out of a recognition that the source and importance of his field lie not in the academy but in private and public life, where what people think, feel and do make all the difference there is...[21]

Callahan remains convinced that it is a proper task of bioethics to subject such things as experience and traditions to critical analysis, seeking reasons and justifications for the decisions and principles thereby proposed. But he goes on to conclude that:

> Nonetheless, in the matter of the case, these justifications might not be forthcoming, if only because they may be falsified if pressed into a verbally articulated form...[22]

C. Bioethics as interdisciplinary

The third of the dangers indicated above is that bioethics is tempted to downplay or lose its interdisciplinary thrust. In the view of this writer one of the distinctive achievements of bioethics to this point is precisely its interdisciplinary methodology in scholarship, in health care institutions and policy formulation. Bioethicists (whether of theological or philosophical "persuasions") and bioethical literature and workshops have undoubtedly been largely responsible for the growing awareness of the ethical dimension of many medical and biological issues on the part of lawyers, physicians, nurses, researchers, sociologists, historians, and bioethics to a large degree has been the catalyst for discussions, reflections and policy-making involving all these and other disciplines and groups.[23]

That healthy interdisciplinary approach could be lost or impeded in two ways. One way would be to "over-professionalize" the enterprise of bioethics. In earlier and simpler times bioethical positions and policies tended to be discussed in relatively informal ways and settings involving not only philosophers and theologians, but as more or less equal partners, physicians, lawyers and others with practical, direct experience in the issues under consideration. But a degree of professionalization has taken place in more recent times, perhaps inevitably but certainly regrettably. A physician, Robert Morrison, has accurately described that shift and result this way:

> Bioethical change is becoming less and less the product of interdisciplinary discussion and more and more the output of single scholars - professional bioethicists... The very burden of new knowledge dictates a high degree of concentrated study that easily becomes a full-time dedication... On the other hand, the biologists and physicians who earlier occupied a relatively prominent place in the new movement now seem less active. Their number was never very large, but it has probably been diminished by

> the embarrassment of trying to compete with the professional philosophers, some of whom have gone so far as to suggest that nothing in medical training fits a person to make ethical judgments.[24]

That quote serves as an appropriate introduction to a second way of impeding healthy interdisciplinarity. It involves an unfortunate by-product of the interdisciplinary nature of bioethics and the addition of so many new players to the field. It is the danger of obscuring and confusing the special roles of each discipline as regards decision-making, and in particular the danger of over-shadowing and paralyzing the physician's role and job as "chief" decision-maker (after and in conjunction with the patient and family of course). A healthy interdisciplinarity would (and does) clarify and delineate the special functions and contributions of each discipline, taking care in actual decision and policy-making not to allow the representatives of one discipline to usurp a function more properly left to or shared with those of another. Working out and carrying out those roles and that interaction with great care and sensitivity becomes all the more important given the more crowded field of those with something (though not everything) to contribute.

It is difficult to assess to what degree this danger is already realized, and whether it could be or could have been averted. As well, there are various views as to whether it is indeed a danger at all or rather a positive and over-due gain that physicians may now be limited in their individual decision-making powers thanks to the new awareness, presence and claims of those from other disciplines.

An American physician with regrets in this regard has perhaps exaggerated, yet persuasively drawn attention to a real danger:

> One might have hoped ... that treatment decisions about the terminally ill would be left to the physician, the patient, and the immediate family, their consciences quickened by the renaissance of moral philosophy. Alas! In many jurisdictions the opposite is true. It is now harder to die with dignity than it was before everybody started talking about it. Part of the problem can be traced to lawyers and district attorneys, some of whom have been appalled to discover that for centuries doctors had been making decisions that lawyers thought had been reserved for due process... The bottom line ... seems to be that doctors are now afraid to do anything that might look to anybody like a lack of unbounded enthusiasm for prolonging any given life.[25]

One doubts that matters have gone as far as that physician claims. Not many have claimed that much, and the evidence suggests it is an exaggeration. As well, recourse to courts has sometimes been for the opposite reason than that suggested above - not to impede physicians from stopping treatment or life support in appropriate cases, but to secure court authorization to allow a patient to die over the objections of physicians. A case in point was that of Karen Quinlan. Nevertheless, the underlying fear behind that claim should be taken seriously - that physicians risk having their legitimate decision-making scope impeded by other professionals, especially law and lawyers, and that they are not qualified or authorized to make ethical judgments and contribute to the formulation of ethical policies.

As evidence that this fear is not without some grounds, consider this observation by a lawyer:

> Are human rights and medical remedies compatible? In a society that values both human rights and medical progress, it should be disturbing to civil rights lawyers that the most eloquent voices raising this question come not from the bar but from the scientific community itself ... Civil rights lawyers have a duty to define the implications of scientific developments for the individual and society.[26]

It is not at all clear why lawyers (or anyone else) ought to be "disturbed" that scientists and physicians rather than lawyers are sensitive to questions about rights. Surely such instances are more to be encouraged than discouraged. It should not matter which discipline raises these questions - only that they are indeed raised and resolved. In fairness to that writer, perhaps he is regretting that lawyers are not as sensitive to these ethical concerns as physicians and others (justifiably) are, in which case one could readily agree, but the implication appears to be rather that these matters are best left to lawyers.

Given the goals referred to at the start of this section, following chapters in this Part One will include these topics: the Hippocratic Corpus and more recent medical codes of ethics, theological bioethics, secular bioethics, the similarities and differences between them, and the unique nature and contribution of theological bioethics.

Chapter II: The Hippocratic tradition - medical ethics in the professional codes

1. Its positive and enduring elements - respect for patients, limits of medicine, the virtuous physician

The Hippocratic Corpus is an appropriate place and time to locate the start of our summary effort to identify and compare the strands of bioethics relevant to treatment decisions and policies regarding newborns. Clearly we could not expect to find in fifth century Greece detailed ethical rules and policies to match the moral and medical complexities of modern neonatology. Nor are physicians likely to be consciously aware of or refer to the Hippocratic Oath and precepts in making treatment decisions in a neonatal unit of a modern hospital. It is equally true that there are a number of "missing" elements in that Corpus by present standards, as we shall briefly indicate. Nevertheless, probably no profession has been as attentive to the codes of conduct of its members and for as long a period of time as has the medical profession. As well, whether in the conscious mind or not of the modern physician, the Hippocratic Corpus has been a major influence on later medical codes and thereby still exerts a degree of very real albeit, residual and subtle influence.[27] We can therefore expect to find already in that Corpus at least some general principles and exhortations helpful towards the ethical criticism of present practices and policies regarding newborns.

There is a voluminous literature on the subject of the Hippocratic Corpus, both regarding its historical authorship and its relevance today.[28] What follows on that Corpus is however highly selective and summary given the discrete issue being addressed in this thesis. No effort is made in what follows to deal with historical questions of authorship or origin, or to present a comprehensive picture of that Corpus. Let us begin by listing and briefly describing what in this writer's view are the positive and enduring principles, maxims and exhortations relevant to our issue, and then indicate in what respects the Hippocratic ethic is incomplete by present standards and needs.

A central and enduring feature of the Oath and other parts of that Hippocratic Corpus, largely written from the fifth to the fourth century B.C., is first of all the respect insisted upon for the patient. The most frequently recurring theme is that the physician's duty is to help the patient and avoid doing him harm, and to direct all his abilities and judgment to that end. The Hippocratic ethic insists upon the physician's fidelity to the patient. These excerpts are examples of that theme and that insistence:

> I will use treatment to help the sick according to my ability and judgment, but never with a view to injury and wrong doing ... Into whatsoever houses I enter, I will enter to help the sick, and I will abstain from all intentional wrong-doing and harm....29

> ... Where there is love of man there is also love of the art.[30]
>
> As to diseases, make a habit of two things - to help, or at least to do no harm.[31]

A second related and equally relevant aspect of the Hippocratic ethic is its awareness of the limits of medicine. We see this most clearly in the definition provided for medicine:

> ... I will define what I conceive medicine to be. In general terms, it 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...[32]

The physician is also supplied with a response to those who might say that medicine refuses to take desperate cases but only those which would cure themselves:

> ... if a man demand from an art a power over what does not belong to the art or from nature a power over what does not belong to nature, his ignorance is more allied to madness than to lack of knowledge. For in cases where we may have the mastery through the means afforded by a natural constitution or by an art, there we may be craftsmen, but nowhere else.[33]

Another indication of the importance ascribed by the Hippocratic ethic to knowing the limits of medicine and practicing accordingly is the maxim already quoted above,

"... at least do no harm". Its exact meaning and implications have been and are the subject of much discussion and debate, but at the very least it would appear to be an admonition to humility, to the awareness that respect for the patient sometimes involving not availing oneself of all the medical tools and resources available because the patient will be harmed not helped. One is inclined to agree with this interpretation and application of the primum non nocere maxim:

> ... we may see it, not so much as a morality of lower limits, but as an admonition to humility. When good persons possess great powers and wield them on behalf of others, they sometimes fail to recognize the harm done as they ply their beneficient tools. The medical profession has such power and has, most often, the intention of using it well. They must become sensitive to its shadow side.[34]

The application of this Hippocratic theme of medical limits or medical humility to our issue of the selective non-treatment of disabled newborns, is obvious and important. Recalling and applying this exhortation will not of course solve the further and thorny ethical question of which prognoses should indicate non-treatment or how should we balance a decision for non-treatment with the interests and wishes of other interested parties, but it does at least provide a reminder and authority from a very traditional and highly respected authority that non-treatment can sometimes be medically and ethically indicated.

It is worth noting that at least two influential bioethicists in recent years, one a philosopher, the other a theologian, have in large part based their justification for not sustaining some seriously disabled newborns, on the "at least do no harm" principle.[35] We will consider and evaluate their views at a later point in this thesis.

A third theme of the Hippocratic ethic worth noting is its focus on the physician as a "virtuous" man. As has often been observed, the Hippocratic Corpus contains much that is more in the nature of "etiquette" than "ethics", the former being conventional rules for external behaviour. But there is also a great deal there which goes beyond etiquette and is very emphatically about the moral character of the physician. To a large degree the Corpus is an effort to identify the virtues proper to the physician, and an exhortation to the physician that he practice them in order to merit the trust of his patients. It is in fact these calls to virtue which justify calling the Hippocratic Code (and subsequent medical codes) codes of ethics. Without this focus on virtue underlying and running through the Corpus we would indeed be left largely with etiquette.

The Corpus is full of exhortations to modesty, sobriety, patience, piety, personal honour, benevolence, delicacy and fearlessness, to mention some of the virtues.

In the Oath, the physician swore, "I will keep pure and holy both my life and my art". In another section it is stated that:

> The prudent man must also be careful of certain moral considerations - not only to be silent, but of a great regularity of life, since thereby his reputation will be greatly enhanced; he must be a gentleman in character, and being this he must be grave and kind to all.

Of particular interest in this regard is that in recent and extant medical codes, for example those of the Canadian Medical Association and the American Medical Association, exhortations to virtue have more or less disappeared leaving only some perfunctory remnants. That disappearance suggests two things, one being that there now exists a "... fundamental uncertainty about the character desired in the person who would practice medicine",[36] and that the exercise of reflecting upon the virtues specific to physicians evidenced in the Hippocratic Corpus and subsequent medical codes has now been abandoned. That may have been inevitable given the pluralism in today's medical profession, and many physicians today undoubtedly would find such exhortations and reflections meaningless, superfluous and intrustive. But it is at least arguable that the absence of such reflection and reference in today's medical codes contributes to or at least reflects the depersonalizing of care, the replacement of physician patient trust with technical skills, so often complained of in our times.

If there is any truth to such surmising, then there is no better time to recall and re-kindle that focus on the virtues of physicians to be found in at least rudimentary form in the Hippocratic ethic. Given the complex ethical challenges in present-day medical issues such as treatment decisions for disabled newborns, the need for the virtuous physician who makes trust and duty major priorities could hardly be more obvious.

A last theme worthy of note in the Hippocratic ethic involves the position taken on a number of substantive issues, for example the prohibitions of euthanasia and abortion. Of particular interest is not (just) those prohibitions in themselves, but the fact that in doing so a radical stance was being adopted in that contemporary society, a society which generally tolerated infanticide, abortion and the giving of poison. The Corpus was thereby also judging contemporary mores and the pagan ethos of its time and place, and proposing a code of virtue and conduct based on a humanistic ethos.[37]

This focus as well is potentially relevant to the stance and role of medicine in our times in that there is precedent to be found there for medicine and/or individual physicians standing against prevailing views and practices which violate human dignity and respect for patients. That may well encompass the disabled newborn issue insofar as in many quarters the argument is made that they should be allowed to die or killed because they do not qualify as human beings.

2. The missing elements - a theory of values, patient autonomy, disclosure, equal access, social and institutional ethics

Not surprisingly, the Hippocratic Corpus is silent regarding a number of ethical principles and priorities generally acknowledged in more recent times to be central to medical decision-making. That is of course hardly surprising given the cultural and social ethos of fifth and fourth century Greece. More surprising and regrettable is the relatively little attention given to these ethical priorities in modern medical codes of ethics, despite the frequent revision and updating of those codes.

For example, we do not find in the Hippocratic Corpus any reference to the underlying values or theory of values behind its exhortations and rules. The possibility of conflicts in values, or principles or interests is not addressed or even hinted at. Stating ethical obligations as absolutes with few or no justifications provided is understandable given the more homogeneous society and the relatively few medical treatment options available to pre-technological medicine. But in our more pluralist society with its competing values and interests and its vast array of treatment technologies and options, the Hippocratic ethic clearly must be evolved, both in the direction of making explicit the theory of values underlying the ethics it advocates, and by acknowledging that the ethics of the profession or the physician alone can no longer decide all the issues.

Which brings us to a second and related feature worth noting about the Corpus - it contains a large dose of medical paternalism. It simply assumes that the physician's values (or those of medicine) will decide the issue and that this decision will be acceptable to the patient. The physician's judgment (alone) will determine what is of benefit to the patient. The likeliest example of that position is to be found in the Oath: "I will use treatment to help the sick according to my ability and judgment...". (Emphasis added.) The possibility that the patient in question (or the patient's family) might not agree, and that the patient's (or family's) values and wishes might take precedence and lead to a different course of action (or inaction) does not seem to arise in the Corpus. It is quite emphatic in its insistence that the physician owes respect and care to the patient, but that respect does not yet extend to acknowledging patient autonomy and self-determination. It is not unreasonable to suggest that the still somewhat reluctant acknowledgement by many physicians that patients (or families) have a right to refuse medically proposed treatment, can at least in part be traced back to that earliest and still revered version of the Hippocratic ethic.[38]

A third ethical principle not to be found in the Hippocratic Corpus is that of truth telling or disclosure. In fact, it is not simply silent on that point, it explicitly exhorts the physician <u>not</u> to disclose information to the patient. It states, that the physician should, "Perform all this calmly and adroitly, concealing most things from the patient while you are attending to him ... revealing nothing of the patient's future or present condition".[39] In this injunction we find further confirmation of the point just made - that it will be the physician alone who determines patient benefit with no need to attend to patient autonomy or self-determination. That being so, it follows logically that truth telling and disclosure are not called for and deception is legitimate. Concealing the truth is then made into a positive virtue and what we have come to know as "therapeutic privilege" was the rule not the exception as today. What matters is not patient self-determination but results.

> For many patients through this cause [i.e. truthful disclosure] have taken a turn for the worse, I mean by the declaration I have mentioned of what is present, or by a forecast of what is to come.[40]

As for the present day medical codes of ethics, they no longer urge the physician to conceal the truth, but they generally contain no direct and unambiguous exhortation to disclose truthful information essential for patient (or parental) decision-making. As an example, the CMA Code of Ethics says only of the physician (on the subject of diagnostic procedures): "He will recognize his responsibility in advising the patient of his findings and recommendations".[41]

Equality in the treatment of patients is yet a fourth ethical element given somewhat muted consideration in the Hippocratic Corpus. It is not however quite accurate to claim as does Sissela Bok for instance, that, "... the <u>absence</u> of any thought that the physician should care equally for all is very striking in the Hippocratic Oath...".[42] True equality is not referred to in the Oath itself, but in the wider context of the Hippocratic Corpus introduced by the Oath, equality in treatment is indeed called for, if only somewhat indirectly. There is especially the following:

> Sometimes give your services for nothing, calling to mind a previous benefaction or present satisfaction. And if there be an opportunity of serving one who is a stranger in financial straits, give full assistance to all such. For where there is love of man, there is also love of the art.[43]

The closest that the C.M.A. Code of Ethics comes to an affirmation of equality in treatment is the following (placed under the heading, "Choice of Patient"):

> [An ethical physician] will recognize that he has a responsibility to render medical service to any person, regardless of colour, religion or political belief; shall, except in an emergency, have the right to refuse to accept a patient; will render all assistance in his power to any patient where an urgent need for medical care exists.[44]

By comparison with the quote from the Hippocratic Corpus regarding equality, that C.M.A. Code exhortation is considerably less emphatic and eloquent. As well, it is somewhat ambiguous on several counts. For example, may an ethical physician refuse to treat a person unable to pay (directly or via an insurance plan) if not judged to be in "urgent need"? And who is to judge whether the need is urgent, the physician or the patient?[45]

The ethical principles of the Hippocratic Corpus are essentially individualistic - they decree conduct between a single physician and his patient, and between individual physicians. A fifth element therefore missing is the dimension of social ethics. The difficult but inescapable task confronting medicine today of having to balance the physician's responsibility to individual patients with other responsibilities to society generally (without compromising the former) was simply not one perceived by medicine or society at that time. But in our times and with regard to issues such as the treatment of newborns and many others there are important questions of social ethics to be grappled with. The distribution of both the actual costs of treatment, and the post-treatment burdens of supporting the disabled, to all members of society and no longer just the patient (e.g. the newborn) and his family, are forcing medicine and society generally to formulate balanced, fair and socially responsible treatment policies. There is as well the thorny ethical problem of the fair allocation of ultimately limited medical resources, both in given institutions and society generally. What health needs should be given priority, basic, less expensive health care for the many, or special, expensive surgery and treatment for a few (e.g. seriously defective newborns)? Should the priority be on preventive medicine (such as more effort to ameliorate the environmental causes of fetal and newborn defects), rather than on curative medicine and rehabilitative medicine (such as surgery and support services for seriously disabled newborns)? These and other issues within the purview of social bioethics are not of course only for physicians and medicine to resolve. But given the unique position and experience of physicians they have an equally unique and indispensable contribution to make towards them.

As for the Hippocratic ethic of our times, at least in the form of medical codes, they continue to give relatively little attention to this social dimension, and usually in terms too general to provide any effective ethical direction given the complexities of those issues. An example is the C.M.A. Code of Ethics. Under the heading of, "Responsibilities to Society", an ethical physician is urged to:

> strive to improve the standards of medical services in the community. He will accept his share of the profession's responsibility to society in matters relating to public health, health education, and legislation affecting the health or well-being of the community....[46]

These exhortations are undoubtedly praiseworthy, but what remains is to spell out with some specificity exactly what is the "profession's responsibility" in the matters indicated.

A last element equally missing from the Hippocratic Corpus and the Hippocratic ethic generally is attention to the realities and complexities of the institutional context in which medicine is for the most part practiced today. Again, that is hardly surprising as regards the Hippocratic Corpus itself given the time and times of its formulation. But today, given that health care tends to be provided in institutions, and by teams rather than in the home and by an individual physician alone, there are many new and urgent ethical problems to be faced. Because treatment and decision-making are now more diffused, so is responsibility. Any ethical analysis which ignores the institution and team dimension today is clearly inadequate. Among the ethical questions to be resolved are these: how should treatment, disclosure and decision-making responsibility be assigned and distributed in this context, what are the responsibilities and rights of the institution itself, how should the health care institution and the health care teams provide for the disclosure of information to interested and vital parties such as parents, and for their role in decisions and choices, how should the benefits and needs of patients and families be best responded to given that institutional context and its largely impersonal, technological nature?

Clearly these issues cannot and should not be resolved by physicians alone. The hospital administration, other professionals such as nurses, and in some manner and degree the public itself have their rightful and helpful contributions as well. But to some extent at least, given the "front line" role of physicians, and the desire of the medical profession to be in large part self-regulating, it would seem to be the responsibility of medicine to at least debate and propose codes of institutional ethics, of team ethics.

To this point medical codes of ethics are not helpful on these issues. For example, the closest that the C.M.A. Code of Ethics comes to them are these admonitions to the ethical physician - to seek additional opinions when indicated, and to "support the opportunity of his confrères to obtain hospital privileges in his community...". There can hardly be considered in any sense even an acknowledgement of the institutional context much less even a general statement towards sorting out rights and responsibilities which arise in that milieu. The picture assumed in the codes continues to be the largely non-existent one of an individual physician advising and treating his patient. The individualistic language alone of the Code would seem to support that conclusion - it is replete with expressions such as, "he has a responsibility", "procedures he believes necessary", "he will assure himself".

By way of linking this section to the next (theological bioethics), brief mention should be made of an early Christian version of the Hippocratic Oath. It is entitled, "From the Oath According to Hippocrates in so far as a Christian May Swear It", and probably dates from about the tenth or eleventh century.[47] It remains very faithful to the contents and core of the original Hippocratic Oath, for instance in its promise to, "use treatment to help the sick according to my ability and judgment", its prohibition of euthanasia and abortion, and the insistence upon the physician leading a virtuous life. There are some differences as well, though they could hardly be considered substantial. Whereas the pagan version began with an invocation to various pagan deities, the Christian version displaces them and begins by praising God the Father and Jesus Christ. As well, the pledge of secrecy has disappeared, replaced by the simple promise to teach the art of medicine, "to those who require to learn it".

Whether or not the original document contained more than just an Oath, we can probably assume given the times that it paid no more attention to the "missing elements" identified earlier than did the Hippocratic Corpus itself.

Was this Christian and medieval version of the Oath greatly influential in its times, does it suggest a strong interest on the part of medieval theologians in matters to do with the ethics of medicine? The evidence would seem to best support a negative answer to both questions.[48] Continuing awareness and use of the Hippocratic ethic appears to have been by means of direct contact by at least some physicians with the original Hippocratic texts themselves, rather than by theological efforts to re-kindle and Christianize the thrust and exhortations of the Hippocratic ethic. In fact most of the documents we do know of from the medieval period touching upon medical practice were exclusively concerned with the regulation of medicine and medical etiquette.[49] There is no hint in them of Christian sources or motivation. Our modern medical Anglo-American-Canadian codes of ethics can be traced, not to Christian antecedents, but directly to the writings of Samuel Bard (1742-1821) and Thomas Percival (1740-1804) in England, and directly to the original Hippocratic Corpus of fourth century Greece.

It remains to the later chapters to determine, evaluate and apply the various positions within the perspective of theological bioethics regarding the discrete question of seriously disabled newborns. For the moment our interest is in determining in a brief and summary manner the principles and values of concern to theological bioethics generally, at least those likely to be relevant to the more specific inquiry to come. Only thereby can we determine with any comprehension what theological bioethics is, how it compares and differs from secular bioethics and what principles and values underlie, or should, its criticism of and contribution to policies focused on those newborn children. One of our concerns in those next chapters will be to determine whether the policies consciously shaped by or influenced by the Judeo-Christian perspective (e.g. those designed for religious hospitals) are true to that tradition and its more recent evolution.

To refer to theological or religious bioethics as "it" can be of course somewhat misleading if left at that. Under that umbrella, at least the Judeo-Christian one of interest to us in this thesis, are bioethicists who write and work in the contexts of three different traditions with some marked differences in emphasis and content - Jewish, Protestant and Roman Catholic. While our direct focus is primarily on those who speak from the last two perspectives, those labels themselves cannot without further qualification accurately capture the variety of positions which exist within each of those traditions. For example, Protestant bioethics includes within its ranks those as different in assumptions and conclusions as Paul Ramsey and Joseph Fletcher, the former identified with normative ethics, and the latter with situation ethics. Roughly the same is also true for Roman Catholicism. Under that heading we find for example a traditionalist such as Bernard Häring along with one at the opposite end of the spectrum on a number of issues, Daniel Maguire. To complicate the job of classification and topic headings still further, a number of bioethicists who are in fact theologians rather than philosophers, do not explicitly ground their bioethics on theological or biblical sources but adopt the somewhat more detached form of argumentation and reasoning of philosophical or secular bioethics.

Despite all the above qualifications, the examination of theological bioethics in the next chapter will consider the subject under the headings of Jewish, Roman Catholic and Protestant bioethics. The justification for doing so despite those qualifications is that there are after all some dominant bioethical themes specific to each tradition. Within space limitations, the views of individual bioethicists who do not identify readily with one or another of those themes in their religious tradition will be indicated as well.

Chapter III: Theological bioethics

1. Bioethics in Judaism

Bioethics in Judaism is essentially rabbinic in nature and interpretation, and its major sources are therefore the Bible, the Talmud and the Responsa. Not surprisingly therefore, most of the contemporary Jewish scholars who write in medical ethics are themselves rabbis.[50] Of all three branches of theological bioethics of interest to us, the Jewish branch is the most explicitly and thoroughly religious in its sources and methodology, and the most uniform in assumptions and conclusions. As well, knowledge of and respect for the medical ethics of their tradition is nowhere as high as in the ranks of Jewish physicians, many of whom were and are themselves rabbinical scholars as well as physicians.[51]

Among the central themes of Jewish bioethics of particular interest to us are the related ones of the sanctity of life and the duty to preserve life and health.[52] Behind the duty to preserve life, indeed underlying the whole enterprise of medicine, is the Jewish emphasis on the value and sanctity of life. Each human life is a gift from God and therefore a single life has the same value as many lives. A favourite text making that point is this Talmudic passage referring to the creation of Adam:

> Therefore only a single human being was created in the world, to teach that if any person has caused a single soul of Israel to perish, Scripture regards him as if he had caused an entire world to perish; and if any human being saves a single soul of Israel, Scripture regards him as if he had saved an entire world.[53]

As Bleich and others remind us, Jewish law and moral teaching make of the duty to preserve life one which is an unequivocal and absolute obligation. Human life is an absolute good in itself, not simply as a condition of other values. Even life with great suffering is preferable to the cessation of that life.

Since man is only the steward of life received from God, over which he possesses no absolute title he must preserve and dignify it under all circumstances, his own life and that of others. Even just the remote possibility of saving a life means it must be done, even if it means suspending most religious precepts to do it; the quality of life resulting is not to be considered, nor is the length of that person's life expectancy. A biblical basis of this obligation of saving the life of an endangered person is Lev. 19:16, "Neither shalt thou stand idly by the blood of thy neighbour".[54]

This insistence in Jewish teaching that the quality of life comes from its creation by God not its health or abilities, is well illustrated by this affirmation by Tendler:

> ... 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 of no less value than a person who has 60 years to live ... a handicapped person 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.[55]

Though sickness is viewed as part of the divine scheme and will (either as punishment, expiation for sin or some other purpose known to God), rabbinic teaching, basing itself on biblical authority, permits human intervention in the form of medical treatment.[56] As for life-saving interventions, additional biblical and Talmudic authorities serve as the basis for a physician's obligation to render medical assistance.[57]

To further illustrate Jewish commitment to the sanctity of life and the preservation of life, not only is active euthanasia strictly forbidden, but treatment may be withdrawn only when death is imminent and dying is in its final phase. Nothing at all may be done to hasten death even to a person for whom death is imminent.

To illustrate that injunction, Rosner provides the following quote from the Code of Maimonides:

> One who is in a dying condition is regarded as a living person in all respects... He is not to be rubbed or washed, nor is sand or salt to be put upon him until he expires. He who touches him is guilty of shedding blood. To what may he be compared? To a flickering flame, which is extinguished as soon as one touches it. Whoever closes the eyes of the dying while the soul is about to depart is shedding blood. One should wait a while; perhaps he is only in a swoon.[58]

The duty to preserve life has its serious implications for the patient as well, in that patient refusal of life-saving treatment is not in rabbinic law a justification for not beginning it or ceasing it. The obligation to preserve life applies to the patient as much as to physicians, and if preservation of that life is remotely possible some Jewish sources maintain that it could be forced on that patient over his protests.[59]

The imperative imposed on parties other than the sick person by the Jewish commitment to the sanctity and preservation of life is illustrated by the uneasiness in some sources about even praying for the death of those in great suffering with incurable diseases. The Talmud appears to consider it praiseworthy to pray for the death of such a person, but a responsum limits that activity by teaching that only totally disinterested parties may make such prayers, excluding therefore spouses, family, children and those caring for the patient. The reasons given are first of all that because these parties are emotionally involved, such prayers may encourage doing overt acts to shorten that life, and because these parties are so involved they would not be able to make detached objective decisions focusing only on patient benefit.[60]

There is of course much more which could be said about these and other themes in Jewish bioethics, and about how they apply to seriously disabled newborns. But further qualifications and the application of these principles and general observations to the newborn context will have to be postponed until Chapters VI and VII.

2. Roman Catholic bioethics

Roman Catholic bioethics, like Catholic moral theology of which it is a descendant and branch, draws its principles, methodology and positions largely from the dual sources of a highly systematized theology and hierarchical authority. Especially by the 1950's Roman Catholic medical ethics was a well established discipline in Europe and North America, as evidenced by the large number of writers and influential medical ethics texts,[61] as well as a number of reviews exclusively concerned with medical ethics.

But that highly productive period was of course preceded by a long history and many stages, each of which has left certain marks on Catholic bioethics.[62] While there is no need to trace that historical background in any detail here, several of those stages and influences are relevant and worth a brief mention by way of better explaining the state and thrust of Catholic bioethics. One of those stages was the flowering of scholastic theology in the writings of Thomas Aquinas (e.1274), who proposed a natural law theory highly influential in Roman Catholic morality generally and medical ethics in particular. A number of summae or treatises in the fifteenth century focused on penitential practices and the duties of various states of life including that of physicians, constitutes another important stage and influence. One of the most influential of these was the summae by St. Antoninus (d.1459) the Archbishop of Florence, containing a large section on the duties of physicians such as diligence, care, competence, duty to tell the dying patient the truth about his condition and so forth.[63] A characteristic of these summae on the obligations for practical living was that of casuistry, something which largely characterized almost all Catholic morals and medical ethics until relatively recently. In 1610 Thomas Sanchez (d.1610) published an extremely influential treatise which included a large number of medico-moral issues directly and indirectly related to marriage. This and other such treatises suggest another characteristic of Roman Catholic medical ethics - a strong focus on, some would say preoccupation with, sexual morality.

Gradually there came into existence works referred to as "pastoral medicine", handbooks on various medical issues dealing with the moral problems faced by physicians, theologians, and priests in order to provide the theologians and priests with knowledge about medicine, and physicians with knowledge of moral principles.[64] The nineteenth century was the full flowering of this new discipline of pastoral medicine.[65] The reasons were probably several. One was no doubt the existence and needs of Church-run Catholic hospitals, and the perceived need to systematize and more or less codify the orthodox positions on these issues. Another was the fact that the fast growing biological and medical sciences were presenting theologians and confessors with many new moral issues to be resolved.

Before identifying the characteristics and major principles of Roman Catholic bioethics relevant to this thesis, it is worth noting that since the period of the 1950's referred to in the opening paragraph of this section, the somewhat monolithic and unchanging face of Roman Catholic bioethics has been evolving significantly. Some of those changes will be described towards the end of this section. For the moment suffice it to note that whereas the official position of the teaching office of the Church has not revised its positions on any of the major moral issues in medicine, a number of Roman Catholic moralists have taken more or less new and independent stances on several issues.

The Roman Catholic moralists and bioethicists who have been the most representative and influential in recent years, and to whom we will be frequently referring in this and subsequent chapters are especially the following: Charles Curran, John Dedek, Bernard Häring, Daniel Maguire, William May, Richard McCormick and John Paris. Others whose influence and major contributions were in a somewhat earlier period will also be referred to from time to time. Among them are: Thomas O'Donnell, Gerald Kelly and Edwin Healy.

A. Two characteristics - the place of natural law, the role of official teaching

There are two more or less unique characteristics of traditional Roman Catholic bioethics which merit mention and description at this point. They involve both methodology and content. The first is the centrality of natural law. To the question as to where ethical knowledge is to be discovered, the Roman Catholic moralist and bioethicist would answer, in the scriptures, in faith, in reason and in the natural law. Curran writes of natural law:

> The human being is an image of God precisely insofar as endowed with reason, free will and the power of self-determination. Through reason the rational creature directs one's own activity toward one's proper end and thus is not passively directed by God to the end. Right reason is able to recognize the threefold natural inclinations within human nature - the inclinations one share with all living things, the inclinations we share with animals, and the inclinations we have as rational beings. Thus the natural reason is understood as human reason directing the individual to one's own end in accord with one's nature.[66]

Central to this theology of natural law is that human reason can arrive intuitively at first principles of the natural law which are sufficiently general to be universally valid, such as, "Good is to be done and promoted, and evil is to be avoided".[67] From such principles are then deduced the secondary principles, such as killing is wrong. The traditional view is that these secondary principles cannot be changed substantially without violating the natural law, though they can always be more clearly stated and understood. From secondary principles are then deduced what are sometimes called particular applications, for example prohibitions against direct abortion, active euthanasia, contraception and so forth. Some argue that none of these particular applications can ever be substantially changed,[68] though they would be increasingly in the minority.

Another more recent expression of the Roman Catholic natural law theory relating natural law to other sources of ethical wisdom involves some distinctions suggested by McCormick.[69] He distinguishes several levels and senses of Christian morality or ethics. There is first of all essential ethics, demands seen as of valid application to all persons simply as human persons. Then there is existential ethics, moral claims which apply to an individual as an individual, that is, in view of that person's unique capacities, circumstances, etc. Then there is a level of ethics which could be called, essential Christian ethics, including those demands which apply to all Christians as Christians. Finally there is existential Christian ethics, moral imperatives applying to an individual Christian in view of his responsibilities, state in life, etc. (e.g. as a Christian physician, layman or priest). Though he does not use the expression "natural law", he is referring to it in other terms when he writes of the first sense (essential ethics):

> At this level it has been a Catholic Christian conviction at least since the time of Thomas Aquinas that revelation and the faith experience originate no concrete moral demands that are in principle unavailable to human insight and reasoning. This means that there is a material identity between Christian moral demands and those perceivable by reason. Whatever is distinct about Christian morality is found essentially in the style of life, the manner of accomplishing the moral tasks common to all men, not in the tasks themselves.[70]

We will have occasion to return below to these and other distinctions and points made by McCormick in that analysis as they are of considerable relevance to the issue of just what it is that Judeo-Christian bioethics can best contribute to policies in pluralist settings.

The second unique characteristic about Roman morality and bioethics to be observed here is the influence and place of the Church's official teaching office in these matters. Despite the teaching that the natural law can be known by all man, the existence and authority of this teaching office is defended on the grounds that due to human weakness and sinfulness, humans need the aid of divine revelation and that teaching office to know the natural law. The issue here involves the teaching function in bioethical matters of the Pope, bishops and general councils. As Curran observes, "It is generally acknowledged that teaching in the area of medical ethics does not fall under the category of infallible teaching, which is in reality very limited".[71]

The question then is, of the non-infallible gradations of the Church's teaching office, how are they thought to apply to these bioethical issues? The principal among these teaching forms and gradations are: papal encyclicals, papal addresses, and rulings by various popes who have made a number of pronouncements on issues of medical ethics. One of these popes was Pius XII, undoubtedly the Pope with the greatest interest in these matters. His various addresses greatly influenced the directions taken and encouraged much interest in the problems and medical ethics generally. The traditional answer as to the authority of these papal addresses and decisions by various Roman congregations is that though not infallible, they nevertheless are owed the religious submission of "the intellect and will" (as opposed to the assent of faith owed to infallible pronouncements).[72] In other words, the traditional answer was (and is) that dissent is not allowed with regard to the various issues pronounced upon by the popes, such as artificial insemination, contraception, transplants, medical research, preserving life and so forth.

It should be noted however that regarding both these characteristics, natural law and the official teaching of the Church, there have been important developments in recent years, indicating a move away from the more rigid positions on both. As regards natural law, many Catholic ethicists and bioethicists would agree with this observation by the Protestant bioethicist, Kenneth Vaux:

> The greatest challenge facing Catholic medical morals is to distinguish the unnatural from the natural as the latter is enriched by the range of creativity.... The fundamental question of qualitative human life forces this noble tradition to grapple with the profound ambiguities of modern biomedicine without the benefit of a black and white casuistry.[73]

Among the criticisms and proposals articulated by Roman Catholics concerning the natural law concept are, that it must be open to development, more inductive rather than exclusively deductive in method, escape excessive focus on the purposes of particular faculties at the expense of the total person, and that there must be a move away from the "...physicalism of the older approach, according to which the moral aspect of the human act is identified with the physical aspect of the act".[74]

There have been developments as well regarding the role of official teaching authority. The possibility of dissent from official teachings of popes and congregations in matters of medical ethics was evidenced in the objections of many theologians, lay people and national conferences of bishops to the argumentation and prohibitions of the 1968 encyclical Humanae Vitae. That document upheld the prohibition against "artificial" contraception. As well, influential theological challenges have been made in works of Catholic medical ethics to the official positions on most issues of medical ethics, including, when life begins, contraception, in vitro fertilization, sterilization and euthanasia, despite the fact that on all these issues the position of the official teaching office of the Church remains essentially as it was. The general view of many Roman Catholic bioethicists today is that with regard to moral questions the teaching office of the Church can never be so certain of its positions that all possibility of error is excluded.

B. Two principles

We turn now from some general characteristics regarding methodology and authority, to two moral principles which provide an overview of the content of Roman Catholic bioethics. There are of course a large number of moral principles which could be isolated as central but these two are arguably the ones most relevant to the interests of this paper. They are: the sanctity, dignity and inviolability of human life, and the principle of double effect.

i) The sanctity of life

As in Jewish bioethics, there is much stress in Roman Catholic bioethics on the sanctity of life, and traditionally from conception to death. Only God, the creator of all life, has dominion over life, and humans are only stewards over their own lives and those of others. The value of a life comes not from one's abilities or the state of one's health, but from the value placed on it by God, its creator. Two major implications follow from this in the Roman Catholic perspective. One is that all human life, from conception onwards, has as an inalienable right, the right to life. That in turn leads to a prohibition and a duty. The prohibition is against taking the lives of others, in the medical context by means of active euthanasia.[75] As well, normally physicians, parents and some others have a duty to preserve the lives of others if they are able to do so. The other moral imperative flowing from the sanctity of life principle and man's stewardship rather than dominion over life is that suicide is prohibited.

But the sanctity of life principle and the duty to preserve life are not in the works of most Roman Catholic bioethicists meant to be rigidly applied without attending to the particular circumstances of each case. An absolute or vitalistic interpretation of the sanctity of life principle is foreign to the mainstream of Catholic bioethics. Such an interpretation holds that where there is human life, even mere metabolism and vital processes, no matter what the patient's (or newborn's) condition and prognosis, it would be a violation of the sanctity of life principle either to cease to preserve it or hasten death.

There are essentially two related ways in which the sanctity of life principle is explained and applied in Catholic bioethics as regards treatment of the sick or dying. One line of argument is that as a general rule no one has an obligation to use (or accept) extraordinary means to preserve life. The distinction itself between ordinary and extraordinary means has a long history in Catholic bioethics, going back to the seventeenth century writings of Cardinal de Lugo. More recently the distinction and rule was argued by Gerald Kelly, it has also been endorsed by a number of papal statements on the subject of caring for the sick and dying, and in one form or another is a distinction and rule accepted by most Roman Catholic and many Protestant bioethicists. As expressed by Kelly, what is meant by extraordinary means are all medicines, treatments and operations which cannot be obtained or used without great pain, expense or other inconvenience or which, if they were used, would not provide a reasonable hope of benefit to that patient.

A still more contemporary manner of applying the sanctity of life principle and qualifying the duty to preserve life is by reference to the "quality of life". In reality this might be in effect only another way of expressing essentially the same criterion as that involved in the ordinary/extraordinary distinction. Applied strictly at least, a quality of life criterion focuses only on the (medical) condition and prognosis of the patient. To judge that the quality of that life is too low or too damaged to justify starting or continuing a particular life-saving treatment, is essentially the same as deciding that because it does not offer a reasonable hope of benefit, it is extraordinary and not indicated or necessary. There is, however, a degree of suspicion and hesitation in some Roman Catholic (and other) quarters about the use of quality of life indicators in life-saving or life-sustaining treatment. The hesitation is that there is something in the expression "quality of life" which seems inherently at odds with the sanctity of life and/or that the expression and criterion is too elastic, too loaded against the equality of all lives, too likely to escape the bounds of strictly medical indications and patient benefit, to include economic factors as well as familial and societal benefits.[76]

Most Roman Catholic bioethicists do in fact restrict quality of life considerations more or less to the strictly medical indications and patient benefit, excluding as decisive factors in decisions about life-saving treatment the benefits or burdens implied for others or society generally. To consider a patient's quality of life in that sense is not generally seen in Catholic writings as in any sense a violation of the sanctity of life principle, but on the contrary, as respectful of that sanctity in that it would be disrespectful and idolatrous of life not to acknowledge that under certain circumstances there is no hope of benefitting a patient by continuing treatment. McCormick for instance expresses it this way:

> In the past the Judeo-Christian tradition has attempted to walk a balanced middle path between medical vitalism (that preserves life at any cost) and medical pessimism (that kills when life seems frustrating, burdensome, "useless"). Both of these extremes root in an identical idolatry of life - an attitude that, at least by inference, views death as an unmitigated, absolute evil, and life as the absolute good. The middle course that has structured Judeo-Christian attitudes is that life is indeed a basic and precious good, but a good to be preserved precisely as the

> condition for other values. It is these other values and possibilities that found the duty to preserve life and also dictate the limits of this duty. In other words, life is a relative good, and the duty to preserve it a limited one.[77]

Two points should be noted here with regard to that quote. First of all, it is not quite accurate to claim as does McCormick that the middle path he indicates is "Judeo-Christian". It is Christian, but not Jewish. As already noted earlier, in Jewish law and moral teaching the value of human life is supreme and absolute, and is given precedence over all other considerations. There is no "balanced middle path" in Jewish teaching. Human life is not a good to be preserved as the condition for other values - in that tradition it is an absolute good to be preserved in its own right.

Secondly, in this section and chapter we are basically only indicating the general principles and positions of the various traditions of ultimate relevance to treating disabled newborns. It remains to the following chapters to raise the truly more difficult and specific questions such as what exactly are "those other values and possibilities that found the duty to preserve life and dictate the limits of this duty," and how are they to be articulated in policies in our pluralist society?

To those who consciously or not speak from a "vitalist" perspective on the sanctity of life issue and object to human decision-making and control over human biological processes and matters of life and death, contemporary Roman Catholic theology and bioethics tends to respond that that objection ignores the full dimension of man's role in the world. It is of course true that God is creator, and man is creature, and that only God has dominion over life and death. But man is in a real sense co-responsible for creation, and has been given that mandate by God according to Genesis 1:28. Of course that mandate is meant to be exercised responsibly and within limits, and determining those duties and limits requires much reflection in the light of scripture, tradition and Church teaching. But it is not "playing God" to accept the God-given responsibility to make medical decisions, including stopping or not starting life-support treatment when not indicated. To do so is rather "being humans".[78]

A final point to be noted under the sanctity of life heading is that in Roman Catholic ethics and bioethics, while attention has been directed primarily to the duties and rights and sanctity of the individual person, that person is never perceived as isolated from or unrelated to the community. The human person in Catholic theology, ethics and bioethics has individual dignity and value, but also a social character. It cannot be claimed that all the implications of this perception and conviction have yet been identified and grappled with in Catholic bioethics. For example there is yet relatively little reflection in this tradition on duties and rights arising from the institutional context of much modern medicine. But the social character of man is acknowledged in Catholic ethics to have at least two important general implications.[79]

One is that it is wrong to always conceive of the individual in competition with or threatened by ~~the community~~. God's covenant was after all not with an individual, but with a people, and the Bible refers to Christians as a community, a "body". A direct application of this for our issues is that policies involving the rights and duties of individuals should never be formulated as if they were in isolation from the larger community, or as if that community had no rights and duties of its own. At the same time, it is equally insisted upon by most Catholic ethicists and bioethicists that the community can never subordinate the individual entirely to the needs of the former. Sacrifices made voluntarily for the common good are one thing, but decisions to harm an individual for the sake of the larger community are another and are generally rejected. That perspective has obvious and important implications for decisions to treat or not treat disabled newborns, as will be indicated at a later point in this paper.

ii) <u>The principle of double effect</u>

A second important principle in Roman Catholic bioethics is the principle of double effect. The very existence of the principle is an acknowledgment that many moral decisions in the real world involve gaining a benefit at a moral cost and that few actions will have only one effect or exclusively good effects. It is a principle designed to help resolve conflicts in situations where an action will have two or more effects, at least one of which is judged to be bad. May one proceed with the action regardless in view of the good effect desired?

The principle has long been an integral part of Catholic morals and bioethics, and was applied to every conceivable issue from whether one could give a potentially lethal or death hastening dose of a narcotic to relieve pain, to whether one can remove a cancerous uterus if it means the death of a fetus. Applying this principle, the answer to both questions has been in the affirmative, on the grounds that the hastened death or destroyed fetus were not intended, but only indirectly and unavoidably caused in the pursuit of another good. Though that response would seem in both cases to be the right one (at least for a Catholic) simply on the basis of common sense or intuition, over the years the principle has become highly formalized and refined, to the point that certain actions with a good and bad effect can be justified if four conditions are met.

The four conditions are these: the act itself, quite apart from its effect, must not be morally wrong; the good effect should be caused by the act as immediately as the evil effect, in other words, the evil effect should not be simply a means to producing the good effect; the intention must be good, in that the evil effect should not be intended, only tolerated; there must be a proportionately serious reason for doing the act. Though in that detail and formality and under that label, the principle of double effect no longer enjoys the same importance, essentially these same considerations are still those which are operative to one degree or another in most Roman Catholic bioethical analyses. In fact, one would venture to suggest that considerations or conditions similar to these are also intuitively or more or less explicitly resorted to in moral reasoning generally, including in Protestant bioethics. The real difficulties and differences are no doubt located around determining what results are in fact good, and which are evil, and how much evil we are willing to tolerate to achieve a good result. Those questions this principle does not itself answer.

But the principle itself and its conditions is not only a method, a formula for resolving moral conflicts. It also implies a stance, contains some substance. In particular, in view of its conditions, those applying the principle are in effect committed to the view that there will sometimes be good results such as medical progress or better health services for the majority or burdens on society lessened, which cannot be morally justified, if for instance the good effect would be bought at the price of harm to the lives or rights of others. The principle of double effect is in essence a more complicated statement of the following:

> To justify whatever practice we think is technically demanded by showing that we are doing it for a good end .... is both the best defense and the last refuge of a scoundrel.[80]

Clearly the principle is useful mainly in a moral community and system in which what is good and what is evil by way of particular effects is relatively pre-determined and fixed whether by means of natural law reasoning or revelation. This may still be the case in the Roman Catholic community and moral system. But undoubtedly it is becoming progressively less the case, and particularly in the fast developing and highly contentious field of bioethics.

3. Protestant bioethics

Theological bioethics in the Protestant tradition does not possess the lengthy history, the consistency or the development to be found in both Jewish and Roman Catholic traditions. Nevertheless, especially in the last fifteen years Protestant ethicists have been extremely productive, possibly more than those of any other tradition or group. What makes it somewhat difficult to organize a summary overview such as this around major themes linked to theological and biblical sources, is that Protestant writers tend more than those in the other religious traditions to be very different one from another in their focus and conclusions, more remote from the major strands of systematic and moral theology, and less explicit as to the theological or biblical framework influencing their bioethical analyses. Despite all these factors, or in some respects because of them, Protestant bioethics constitutes a rich variety of provocative and compelling analyses on all the bioethical issues of our times, and tends to be more equipped to evolve and to respond creatively to new problems and challenges (without necessarily sacrificing essential Christian convictions) than are either Roman Catholic or Jewish bioethics.

Though the variety in positions and focus range all the way from Paul Ramsey at one end to Joseph Fletcher at the other, it is nevertheless possible to identify some major and common threads running through the works and views of most of those writing from within that tradition. As was the case in dealing with the Hippocratic, Jewish and Roman Catholic traditions, our look at Protestant bioethics in this section will necessarily be summary and selective. Of interest will be only those general themes and sources which will be relevant to our more specific inquiries about disabled newborns in Part Two. Among the theologians and bioethicists of particular importance and influence in this tradition (though in varying degrees) are: Karl Barth, Paul Ramsey, Helmut Thielicke, James Gustafson, Joseph Fletcher, John Fletcher, Stanley Hauerwas and Kenneth Vaux. We will be referring to most of them (and others as well) in this or subsequent sections.

A. The sanctity of life

A first and major principle explicit or implicit in the writings of most Protestants writing about bioethics is that of the sanctity of life. Explicit emphasis on that principle is particularly evident in the works of those who are most explicit about the theological and biblical sources underlying their bioethical positions, expecially Barth, Thielicke and Ramsey.

For Barth, life is sacred and worthy of respect not because of something in life itself by itself, but because of what a holy God has done.

> 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.[81]

That man's dignity is ultimately rooted exclusively in the value placed upon life by God was also affirmed by Thielicke:

> This "alien dignity" expresses the fact that it is not man's own worth - his value for producing "good works", his functional proficiency, his pragmatic utility - that gives him his dignity, but rather what God has "spent upon him", the sacrificial love which God has invested in him (Dt. 7:7f). Therefore this alien dignity actualizes itself at the very point where man's own value has become questionable, the point where his functional value is no longer listed on society's stock market and he is perhaps declared to be "unfit to live".[82]

Paul Ramsey contrasts the religious position regarding the sanctity of life to the modern view:

> ... 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 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....[83]

Does this commitment to the sanctity of life impose in Protestant bioethics an absolute duty to preserve life at all costs? Not at all. Within this tradition there is almost universal acknowledgement that in some circumstances the obligation to preserve a life ceases and that it would demonstrate lack of respect for the sanctity of that sick or dying person to continue aggressive measures of life-support. But within the parameters of this qualification on the duty to preserve life, there is a wide range of views as to the justifying principles and circumstances. At one more conservative extreme are for example Karl Barth and Paul Ramsey, and at the other more liberal extreme is Joseph Fletcher.

Barth himself initially maintains that the duty to preserve life is in fact absolute. Interestingly enough, his grounds for so concluding are essentially the same as those who argue in favour not just of allowing to die, but also active euthanasia - that there is no moral difference between directly intending a patient's death and allowing him to die. But in Barth's case the "no distinction" argument led him to the opposite extreme of those in favour of killing. Because deliberate killing is always wrong, and allowing to die or "letting life ebb away" are morally the same, the latter is also as morally wrong. To let life go is to deny its sanctity, to declare that it is useless. But as Ramsey observed, in so concluding Barth failed to make a distinction between holding another life to be useless and a treatment to be useless.[84]

But in the final analysis Barth concludes that precisely because of respect for the sanctity of the dying person's life, in some cases the medical prolongation of life can be as disrespectful as actively ending it. He questions,

> Whether this kind of artifical 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. A case is at least conceivable in which a doctor might have to recoil from his prolongation of life no less than from its arbitrary shortening.... For it is not a question of arbitrary euthanasia; it is a question of a respect which can be claimed by even the dying life as such.[85]

Ramsey himself does not hesitate to affirm that there is no duty to use useless means to prolong the life of one who is irreversibly dying, no matter how natural, ordinary or customary the treatment is. That position is composed of several important ingredients and arguments, though not always easily deciphered given his somewhat rambling style. In view of Ramsey's influence and because he represents a major current in Protestant bioethics on death and dying, at least in his setting out of principles to be applied and balanced, those ingredients merit a brief sketch at this point.

There is first of all the question of whether there is a distinction between killing and allowing to die. Ramsey, by answering in the affirmative, agrees with the traditional Roman Catholic position. But he adds a crucially important element not insisted upon as explicitly by other ethicists whether Roman Catholic or Protestant, an element of crucial importance to the issue of treating seriously disabled newborns. In response to those (like Fletcher) who argue that there is no moral difference between allowing to die and killing because in both cases the intention or end in view is the same, Ramsey responds that of course the intention is the same. It is quite true that in both cases death is now accepted and not opposed. But to accept an end does not mean there are no important moral distinctions to be made about means. And allowing to die, stopping or not starting curative or life-supportive treatment, does not mean switching from doing something to doing nothing - when one stops attempting to save and cure one is then free to care for the dying. It is this insistence upon the continuing obligation to care which to a large extent characterizes Ramsey's contribution and underpins his positions, including this distinction between killing and allowing to die. From the Christian perspective allowing to die must always have the words "with care" added. Ramsey himself expresses this conviction as follows:

> The difference between only caring for the dying and acts of euthanasia is not a choice between indirectly and directly willing and doing something. It is rather the important choice between doing something and doing nothing, or (better said) ceasing to do something that was begun in order to do something that is better because now more fitting. In omission no human agent causes the patient's death, directly or indirectly. He dies his own death from causes that it is no longer merciful or reasonable to fight by means of possible medical inter-

> ventions.... We attend and company with him in this, his very own dying, rendering it as comfortable and dignified as possible.[86]

From this perspective, as with the distinction between ordinary and extraordinary care, the important consideration is not the particular medical means used in itself, but whether it is used for purposes of remedy or care. Both very ordinary or natural means (such as food and drink) can be used to make a dying person comfortable without implying any intention to prolong that life. But more "artificial" means could also be used for caring rather than remedial purposes. If for example a glucose drip or still more sophisticated treatment and technology were the only way to avoid dehydration or provide comfort for the last days of a dying patient, then it should be provided. If these means also indirectly prolong that life, that would not be the purpose intended. As for pain-killing drugs which (can) also shorten the dying process, Ramsey (like most Protestant and Roman Catholic bioethicists) sees no moral objection if its use in a particular case passes the test of an act which is "indirectly voluntary". Applying essentially the same test as that involved in the principle of double effect referred to earlier, Ramsey concludes:

> In this case, the justification is that relief of his pain is the "directly voluntary" action, while the administration of the drug shortens the dying process in only an "indirectly voluntary" way. What one does directly and immediately is to help the patient in his insufferable pain. That he dies sooner is not the primary result.[87]

In a somewhat tentative manner, Ramsey acknowledges that there might be exceptions to his moral rule that we should never abandon the care of the dying, never hasten the dying process. One such justification could involve those who are completely and irreversibly beyond reach, those who are not suffering, and beyond care, especially those in a deep and irreversible coma who could live on for many years. The rule for these exceptional cases could be:

> Never abandon care of the dying except when they are irretrievably inaccessible to human care. Never hasten the dying process except when it is entirely indifferent to the patient whether his dying is accomplished by an intravenous bubble of air or by the withdrawal of useless ordinary natural remedies such as nourishment.[88]

For these cases Ramsey sees no difference between commission and omission, for:

> The condition of the patient renders it for him a matter of complete indifference whether humankind's final act toward him directly or indirectly allows death to come. He already is beyond our love and care.[89]

A second exception could involve those in a prolonged dying process in which their severe pain is intractable. Ramsey does not claim there necessarily are such cases, but provides a justification for abandoning care or hastening death if such cases should arise:

> One can hardly hold men to be morally blameworthy if in these instances dying is directly accomplished or hastened. The reasons are the same as those advanced in favor of the first stipulation: A patient undergoing deep and prolonged pain, who cannot be relieved by means presently available to use to care for him and make him comfortable, would also be beyond reach of the other ways in which company may be kept with him and he be attended in his dying - as much so, depending on the degree of his undefeatable agony, as the prolonged comatose patient.[90]

But though Ramsey considers these two exceptions to be morally defensible from a Christian perspective, he remains hesitant about actually including them in medical treatment policies. His fear and question is this:

> Can a doctor and can medicine as a rule of practice admit that a patient is beyond earthly care, inaccessible to care, and so warrant as a practice positive actions that accomplish or hasten his death while not weakening medicine's life-saving mission? Would the doctors who are the moral agents in these exceptional acts of killing the dying, or acts that allow to die, be corrupted by them, and medicine's impulse to save be weakened?[91]

He concludes that if the principles, rules and limits he elaborates are adhered to, he does not believe there is reason to fear that that impulse of medicine to save life will in fact be weakened.[92]

At the other end of the scale as regards the sanctity of life principle and the duty to preserve life is Joseph Fletcher. In effect he argues for the replacement of the sanctity of life principle with a quality of life ethic, maintaining that the two are mutually exclusive. At first sight his position appears similar to those who see the sanctity of life and quality of life as (at least potentially) compatible, for instance the view of the Roman Catholic Richard McCormick referred to above: "... in the balance of biological life and human life, being a man or person is of more value than simply being alive".[93] But for him, as opposed to others like McCormick, the sanctity of life principle has only one possible meaning - it is essentially vitalistic, that is, it means preserving human life no matter what the damage or prognosis because human life and the right to life are absolute values in themselves. His interest is in "needs", not 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 only 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.[94]

He therefore concludes:

> 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.[95]

In Fletcher's view this necessitates a break with both the traditional religious and traditional medical views:

> ... ~~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.[96]

In Protestant bioethics generally, quality of life considerations (or equivalents) are viewed as playing a legitimate role in treatment decisions, much as they do in Roman Catholic bioethics - in both traditions attending to quality of life factors is generally not seen as necessarily a violation of the sanctity of life principle, and in both traditions there is a fairly wide range of views as to the meaning, latitude and scope of acceptable quality of life criteria. On this issue, Joseph Fletcher is clearly at the most liberal extreme in that range of positions, and Paul Ramsey just as clearly at the other end. Among theological bioethicists generally, Fletcher has produced the most explicit and detailed quality of life criteria. These criteria are meant to express in policy form Fletcher's view that what counts is personal function not biological function. Though we will be considering his criteria in greater detail in Chapter VIII, a brief summary is in order already at this point.

Fletcher's proposal was made in two stages, the first in 1972[97] and the second in 1974.[98] In his first stage he advocated fifteen "positive" human criteria and five "negative" human criteria. Those (adults or newborns) falling below or "failing" these criteria would not qualify as human persons and therefore would not qualify for life-supporting or life-saving treatment. His fifteen "positive indicators" are: minimal intelligence, self-awareness, self-control, a sense of time, a sense of futurity, a sense of the past, the capacity to relate to others, concern for others, communication, control of existence, curiosity , change and changeability, balance of rationality and feeling, idiosyncrasy, neo-cortical function. Among his "negative" criteria are: man is not essentially parental, not essentially sexual, not essentially a worshipper. In his second stage, Fletcher reduced the criteria to four: self-awareness, the capacity to relate to others, happiness, neo-cortical function.

His assumptions and criteria were welcomed by some, but also the subject of much criticism. One frequent criticism was that he provides little or no clarification and defence of the moral assumptions underlying the criteria, and no overall theory, theological or philosophical, to provide a coherent justification for producing criteria in the first place and these particular ones. Another criticism was that there is excessive attention to rationality and intelligence with no respect for the complexity and levels of intelligence. He categorically states in this regard that, "True guilt arises only from an offence against a person, and Down's is not a person".[99] About intelligence he says: "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".[100]

For his part, Ramsey is somewhat suspicious of the quality of life concept generally:

> If physicians are going to play God under the pretense of providing relief for the human condition, let us hope they play God as God plays God. Our God is no respecter of persons of good quality ... a true humanism leads to an "equality of life" standard....[101]

Ramsey is against the use of quality of life criteria guidelines in medicine, and takes serious issue on largely biblical grounds with proposals such as Fletcher's. He responds to Fletcher's "indicators of personhood" as follows:

> ... I want first to say that that's no way to play God as God plays God. That was not the bottom line of his providential case. When the prophet Jeremiah tells us, "Before I formed thee in the belly I knew thee: and before thou camest forth out of the womb I sanctified thee; and I ordained thee" (I:5), he does not mean to start on a search for the "indicators of personhood" God was using or should have used before calling us by name.... No more did God, at the outset of his Egyptian rescue operation, look around for "indicators of people hood", choosing only those best qualified for national existence.[102]

Another issue under the heading of the sanctity of life principle is that of active euthanasia. Most Protestant bioethicists, as Roman Catholics, continue to reject it, generally because killing is expressly and biblically prohibited and because to allow it in the medical context even in exceptional circumstances would be the thin edge of the wedge increasingly putting all life and the sanctity of life at risk. Joseph Fletcher is an exception in this regard. He sees no significant moral distinction between killing and allowing to die (the latter termed indirect or negative euthanasia by Fletcher)[103] because the purposes are the same, and argued that direct or positive euthanasia for compassionate reasons is ethically more courageous than is merely allowing a person to die:

> ... ethically regarded, this indirect-involuntary form of euthanasia is manifestly superficial, morally timid and evasive of the real issue ... it is harder morally to justify letting somebody die a slow and ugly death dehumanized, than it is to justify <u>helping</u> him to avoid it.[104]

B. The morality of human interventions

As in Roman Catholic ethics and bioethics, so too in the Protestant tradition, attention has been given to the morality of human interventions in creation, including biomedicine. At one end of that scale, the more liberal end, could be placed the views of Gustafson. His starting point is that God is not only the creator and preserver of life, but it is also God whose power:

> creates the conditions in which new possibilities for well-being occur and in which different actions are required to preserve the well-being of the whole of creation.[105]

Gustafson sees in that fact:

> ... a basis for the alteration of principles and values that have traditionally been adhered to in medical research and care. It provides a basis for re-ordering of accepted values in the light of new conditions when there is warrant for such.[106]

Applying that point to biomedicine, Gustafson acknowledges that while the risks and benefits to individuals, the human community and the whole of creation must be carefully weighed and considered, there may be occasions when the individual can be harmed for the sake of the common good. This is not an open license:

> But neither is human life of absolute value; God wills the well-being of the Creation. Just as there are historical occasions on which human physical life is not only risked but sacrificed for what is judged to be a human common good, for example in the defense of a nation against unjust attack, so also there are occasions in which new possibilities for the well-being of individual persons, the human community, and the whole of creation require action that risks harm, indeed irreversible harm, to individuals.[107]

Applying this to the "do no harm principle", he concludes that:

> There is no guarantee that restraints upon action by a deontological principle "do no harm" to a particular individual or species fulfills the well-being of the creation.[108]

In man's role as "co-actor" with God, responding to the new possibilities created by God:

> ... it is not always possible to be responsible for the well-being of the creation and at the same time to preserve certain rights of individuals that in the

> past were judged inalienable. It is sometimes morally justifiable to alter the order of values from the past in the light of different and novel conditions.[109]

As on other related issues, so too here, Ramsey is at the other end of the scale and utterly opposed to the kind of conclusion to which Gustafson comes. New conditions and challenges must be responded to yes, but that does not imply an alteration of principles and values, or a sacrificing of the well-being and inalienable rights of individuals for the common good. As already indicated, a "common good" bought at that price in his view would not be a good at all. From Ramsey's perspective it would be inconceivable that man's God-given role in protecting and developing creation could involve no longer preserving inalienable rights of individuals. For Ramsey, the well-being of creation willed by God is precisely a well-being in which the welfare of the individual is <u>not</u> traded for that of mankind or the common good. Gustafson's conclusions on that score would seem to fall well within Ramsey's condemnation of those who would say, "that medical advancement is hampered because our 'society' makes an absolute of the inviolability of the individual".[110] Given Ramsey's insistence upon the duty to <u>care</u> for the dying, he is at the opposite pole of anyone who could tolerate <u>harm</u> to any individual for the sake of the common good.

C. The covenant theme

A theme which surfaces frequently in Protestant bioethics is one which sees the relations between physician and patient in terms of covenant. Covenant based upon faithfulness or loyalty is essentially an ethic of keeping one's promises. Covenant faithfulness is the basis of Jewish law, ethics and medical ethics and both Jews and Christians identify themselves in the most fundamental sense as "people of the covenant". In some branches of Protestantism the covenant theme stands out more sharply than in others, and is especially prominent in Calvinist theology. Covenant is undoubtedly the most important and basic aspect of Karl Barth's theology.[111] In Protestant medical ethics Paul Ramsey has been the most explicit in the use of covenant theory, basing himself especially on the theology of Karl Barth.[112]

For Ramsey, covenant or loyalty is the basic element of the moral requirements between people generally in their relationships with each other, and the primary ethical question for all men is, "What is the meaning of the faithfulness of one human being to another in every one of these relations?"[113] Applying covenant to one of those relations, the practice of medicine, Ramsey locates covenant at its very heart and gives it many names:

> The practice of medicine is one such covenant. Justice, fairness, righteousness, faithfulness, canons of loyalty, the sanctity of life, hesed, agapé or charity are some of the names given to the moral quality of attitude and of action owed to all men by any man who steps into a covenant with another man - by any man who, so far as he is a religious man, explicitly acknowledges that we are a covenant people on a common pilgrimage.[114]

Specific medical covenants within medicine are many, among them:

> ... are the covenant between physician and patient, the covenant between researcher and "subject" in experiments with human beings, the covenant between men and a child in need of care, the covenant between the living and the dying, the covenant between the well and the ill or those in need of some extraordinary therapy.[115]

For Ramsey, covenant loyalty is the motive and ground for continuing to care for the dying even after life-saving procedures have stopped. Such caring measures:

> ... are the embodied and effective gestures of soul to soul. As such, mere acknowledgements of solidarity in mortality are due to the dying man from any of us who also bear flesh. Thus do men give answer by their presence and comfort to the faithfulness - claims of persons who are passing through the acceptable death of all flesh.[116]

It is also covenant loyalty to patients which should impede hastening death, that is, euthanasia:

> If we seriously mean to align our wills with God's care here and now for them, there can never be any reason to hasten them from the here and now in which they still claim a faithful presence from us....[117]

> It would be a defection from the faithfulness - claims of a fellow human being that his very own dying be blessed as an event in the human community to which we attend if the dying are hastened beyond the reach of our love and care.[118]

As has been pointed out, this essentially biblical notion of covenant as used by Ramsey goes well beyond what is expected by the Hippocratic ethic, including modern professional codes.[119] Whereas covenant fidelity morally binds physician and patient reciprocally by mutual pledges of loyalty, the Hippocratic ethic only calls on the physician to make a unilateral pledge to benefit the patient according to his judgment.

There is as well an important implication to be noted in Ramsey's use of covenant theory. Without in the least denying the importance and centrality of covenant fidelity, one is struck by its apparent restriction to fidelity between individuals (and not as well applied to social and institutional relationships). As well, in discussing covenant exclusively in the context of physicians, the notion could be implicitly and regrettably reinforced that it is the physician (and not the patient and other interested parties) who is the primary interpreter of what faithfulness to a patient calls for in particular instances, and that the ethical issues to be reflected upon will be those important to physicians.[120]

Whether or not such impressions were intended by Ramsey, it is often conceded by those writing from the perspective of theological bioethics (and philosophical bioethics as well) that bioethics has been too narrow in its concerns.[121]

D. Agape, freedom and the place of rules

Another theological theme running through Protestant bioethics is that of love or agapé. In reality of course it is not a theme completely separate from that of covenant fidelity but, on the contrary is an integral part of it. Ramsey for example uses covenant, agapé, hesed and charity more or less as equivalents, emphasizing the meaning of hesed as "steadfast love".

For Ramsey, moral agents must be free to do virtuous actions out of love, but at the same time he acknowledges an important place in his perspective for moral restraint, rules and principles. He by no means subscribes to the Roman Catholic concept of natural law,[122] yet he does not promote love and human freedom without boundaries, restraints and rules. What calls for these limits and rules to the scope of love and human freedom in Ramsey's views is clearly his distrust of unfettered human will given the sinfulness of man. The acknowledgement of sin plays an important role in Ramsey's bioethics. It is that sinfulness which accounts for tendencies to selfishness and to usurp God's dominion over creation and life, and which accounts for the need for restraints. It is arguable in this regard that covenant in Ramsey's ethics serves not only to bind people together in a consensual manner, but also to restrain man's sinfulness by justifying some more or less exceptionless moral rules and principles to restrain human will.[123]

An example of Ramsey's insistence upon man's propensity to evil and the consequent need to limit the freedom to respond with unfettered love is precisely his position on treating the sick and dying. As has been observed by others, whereas his earlier views gave more scope to the consensual perspective, arguing for adhering to the wishes of patients as to whether to treat or not, his later views promoted as well the application of rules and principles.[124] The patient's wishes are still to be given consideration but within the framework of a "medical indications policy".[125]

In Protestant bioethics no one gives as prominent and unrestrained a place to agapé or love as does Joseph Fletcher. For Fletcher, unlike Ramsey, there are in effect no restraints or rules to expressions of loving concern - what matters is only the consequences. In his own words, his position:

> ... comes down to the belief that our moral acts, including suicide and mercy killing, are right or wrong depending on the consequences aimed at ... and that the consequences are good or evil according to whether and how much they serve human values. In the language of ethics this is called a "consequential" method of moral judgment. I believe that this code of ethics is both implicit and explicit in the morality of medical care and biomedical research. Its reasoning is inductive, not deductive, and it proceeds empirically from the data of each actual case or problem, choosing the course that offers a maximum of desirable consequences.[126]

For Fletcher, it is not only a question of rejecting natural law,[127] but in effect rejecting normative or "duty-ethics" generally. He characterizes and dismisses the latter as follows:

> In duty-ethics what is right is whatever act obeys or adheres to the rules, even though the forseeable result will be inhumane. That is, the highest good is not human happiness and well-being, but obedience to a rule - or what might be called a prejudiced or predetermined decision based not on the clinical variables but on some transcending generality.[128]

Among the various objections made to this perspective on religious and other grounds, is that the approach itself helps us very little in determining what is the loving and compassionate thing to do in a given concrete situation. Since normative principles and rules other than the very general one of "always ensure human happiness and well-being" are ruled out of order, the conscience of the decision-maker in a treatment situation is left with little by way of guide as to what is human happiness and well-being in this situation. That is especially so in treatment decisions for disabled newborns who cannot express wishes or consent as to what they consider would be for their well-being.

His approach tends as well to confirm medical resistance to develop and apply guidelines and codes to assist in making treatment decisions. With some justification Veatch makes this observation about Fletcher:

> ... his appeal to love combined with Protestant notions of individual responsibility for interpreting the Scripture make Protestantism ripe to conspire with professional physician ethics in emphasizing case-by-case approaches. If physicians were wont to say that every case is so unique that no rigid rules apply, some branches of Protestant ethics are eager to provide a theoretical underpinning for that situationalism. Small wonder that Fletcher finds such a warm bed in the chambers of the medical school and the medical profession.[129]

Chapter IV: Philosophical or secular bioethics

In this brief consideration of philosophical or secular bioethics we cannot hope, nor is it necessary for our purposes, to provide a comprehensive and detailed analysis of its principles and purposes. The much more modest aim is simply to isolate and summarize a number of its major characteristics. That will enable us to attempt in the next section a comparison between the two perspectives in order to identify what it is that is unique about the theological perspective of bioethics and to give some attention to how that perspective can be protected and influential in treatment policies designed for a pluralist context.

1. Sources, methodology and goals

This other, to some extent competing, variety of bioethics, is one which is largely philosophical and secular in expression and inspired by a humanistic rather than religious vision of life. We do not include here those bioethical approaches involving analyses and positions essentially similar to those found in explicitly theological bioethics, but more or less stripped of explicit reference to biblical, theological or church authority. They continue to fall more readily under the heading of theological or religious bioethics despite apparent efforts to market them as secular, and are not the ones of interest here. The analyses of interest are those essentially philosophical in framework, methodology and terminology, though some of the fundamental concerns and principles of theological bioethics are often implicitly to be found as well (e.g. "sanctity" of life re-emerges, with some differences, as "dignity" of life).

In relatively few cases may one conclude that an analysis proposed as secular or philosophical is totally dissimilar to or at odds with the concerns and conclusions to be found in one variety or another of theological bioethics. Though there is more concern in the former with matters of procedure and process than with specific and correct answers, principles and preoccupations are often similar. The real differences between the positions proposed by the theological and humanistic perspectives lie not just in the "what" (the content) but more in the "why" (the motivations). That is no small difference but a highly significant one, a subject to be discussed in the next section of this chapter.[130]

The common roots of the various branches and varieties of present day medical ethics in the Judeo-Christian tradition, and (consequently) the amount they have in common is a point made by Ramsey, among others:

> In the first place, the Judeo-Christian tradition decisively influenced the origin and shape of medical ethics down to our own times. Unless an author absurdly proposes an entirely new ethics, he is bound to use ethical principles derived from our past religious culture ... In the second place, whether our moral outlooks are inspired by a humanistic vision of life or by a religious perspective, there may be a convergence between these points of departure on the plane of special moral problems.[131]

It should also be noted that those who do bioethics from the theological perspective will often incorporate and use principles and insights borrowed from philosophical ethics or bioethics. There is of course much precedent for this in earlier times, the most obvious example being the borrowing by Aquinas of Aristotelian philosophy and grafting onto it a Christian perspective to produce his "Christian" scholastic theology. In present day theological bioethics we find Paul Ramsey for example making extensive and approving use of the philosophy of John Rawls on the issue of justice as fairness.[132]

A distinctive feature of philosophical ethics is that its methodology involves (exclusively) the use of reason. It is as a rational science that it weighs and balances various principles, considers consequences, evaluates solutions and so forth. Which does not mean that theological ethics is irrational or non-rational, it is neither. It has long been held by Christians that the "essential" moral demands of Christianity (those which apply to Christians as persons rather than just as Christians) are justifiable on biblical grounds but also perceivable, universalizable, and justifiable on grounds of reason. But whereas the methodology of theological ethics regarding that part of Christian morality not distinctively Christian involves both faith oriented conviction and reason, philosophical ethics is not related to convictions in that sense.

To indicate the role and goals of philosophical ethics or bioethics, one should distinguish between ethical theory, and ethics.[133] Ethical theory has to do with questions <u>about</u> ethics, and under this heading various goals are proposed: analyzing concepts, determining the meaning of and logical properties of words, determining rules of consistency and logic, and so forth. The philosopher R.M. Hare notes that once these tasks are accomplished errors in reasoning such as fallacies and confusions can be avoided, moral questions can be answered with one's eyes opened and the problems will not be as perplexing.[134] But there are other goals as well under the ethical theory headings. They include the determining, ranking and balancing of various principles (e.g. beneficence, autonomy, etc.) and efforts to weave the principles together in unified theories (e.g. utilitarianism, consequentialism, etc.).

As for ethics, as opposed to ethical theory, its goal is that of going a step further and providing, not necessarily answers, but at least directions for moral conduct in specific situations. Whereas some twenty years ago the focus among philosophers tended to be on ethical theory, today the pendulum has swung in the direction of shedding light on concrete ethical problems.[135] The bioethics area is an example of this shift as evidenced by an explosion of philosophical analyses on every conceivable subject in bioethics.

2. Principles and theories

Similarly to theological bioethics, philosophical bioethics cannot of course be reduced to any single principle or principles or ranking of principles, or to any single ethical theory, to which all ethicists will subscribe. Various writers will propose various principles and theories, and ethical "answers" or directions for concrete issues will depend upon how the principles are weighed and balanced and within the context of which ethical theory.

It would probably not be over-generalizing to say that the key characteristic of philosophical ethics generally, including bioethics, is an emphasis on moral rights and the principles of autonomy and self-determination. The roots of this emphasis go back to the start of modern liberal philosophy and the writings of Locke and Rousseau, as well as to Kant. Patient autonomy was not even referred to in the Hippocratic Corpus, nor, until relatively recently was this principle to be found highlighted in any tradition within theological bioethics. In medical law cases, especially those involving issues of patient consent, the courts have strongly underlined the centrality of this principle.[135]

A decision would be considered autonomous:

> ... if it derives from the person's own values and beliefs, is based on adequate information and understanding, and is not determined by internal or external constraints that compel the decision.[136]

Consequently, a principle of respect for autonomy in the medical context means that patients should be allowed to make their own choices according to their own values and beliefs, free from pressures and interventions by others no matter whether those others feel that the risks or predictable results of non-intervention are foolish or wrong.

A second and more or less competing principle and decision-making model central to philosophical bioethics is that of beneficence. Essentially respect for this principle means that the physician should seek the greater balance of good over harm in caring for patients. A clear antecedent of this principle, at least in skeletal form is to be found in various passages of the Hippocratic Corpus, especially these:

> I will define what I conceive medicine to be. In general terms, it 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.[137]
>
> As to disease, make a habit of two things - to help or at least to do no harm.[138]

In the context of medical treatment, Beauchamp suggests a list of goods to be sought and harms to be avoided in applying the beneficence model. The goods and corresponding harms are these: health v. illness; prevention, elimination or control of disease and injury v. disease and injury; relief from unnecessary pain and suffering v. unnecessary pain and suffering; amelioration of handicapping conditions v. handicapping conditions; prolonged life v. premature death.

It is generally acknowledged that the autonomy and beneficence models are in conflict. According to the autonomy principle and model it is the patient who decides about treatment, and his best interests are understood from the perspective of that patient, no one else. But for the beneficence model the patient's best interests are considered from the perspective of medicine, the issue being what is medically the best decision for this patient, the physician therefore being the primary decision-maker. From the perspective of the autonomy model, the primary danger and limitation of the beneficence model is that of medical paternalism. From the perspective of the beneficence model, the inherent danger and limitation of always respecting patient autonomy is that patient decisions may be detrimental to their health.

It is still another principle, that of truth-telling or disclosure of information by the physician to the patient, which underlines the conflict between autonomy and beneficence. It follows from the principle of autonomy that the patient must be in a position to make an informed consent, which imposes on the physician a duty of providing sufficient information. But applying the principle of beneficence, the physician may judge that to disclose information would seriously risk medical harm to the patient, for example inducing depression and jeopardizing recovery.

While it is tempting to settle the matter and apply only the autonomy model or the beneficence model (a view argued by some), the more reasonable view is that the conflict is inevitable and here to stay, that each has an important role to play, and that in some cases the autonomy model is clearly more appropriate while in other cases the beneficence model is justifiable. It is worth noting that though the law places a very high value on respecting patient autonomy and therefore on the importance of informed consent, it also acknowledges that there are times when the physician may withhold information if full disclosure will jeopardize patient health or recovery. Physicians may in such cases in other words invoke a "therapeutic privilege".[139]

The position of the law is therefore that both competing models can be justifiable, that sometimes (by exception) a standard of disclosure based on the principle of autonomy should give way to a disclosure standard based on the principle of beneficence, but at other times (most of the time) a disclosure standard based on the principle of beneficence should give way to one based on patient autonomy.

But when should one model prevail over the other? Who should decide, patients or physicians? Bioethicists propose various answers and criteria, but if both principles are to be valued and both models retained, then the most reasonable general criterion would seem to be this: patients who are substantially capable of making decisions should normally be treated according to the autonomy model - they should be provided with full disclosure and be allowed to decide about their treatment. But for a patient whose ability to make decisions is seriously limited because impaired or undeveloped (e.g. due to advanced dementia, serious retardation, accident or because newly born) the beneficence model should normally apply. In these cases treatment decisions should be based upon the calculation of benefits and harms, and the amount of information to be disclosed would fall within the same calculation.[140]

Applying these general criteria would mean that treatment decisions for the seriously disabled newborn would be made according to the beneficence principle and model. The autonomy principle and model is simply not relevant to newborns. What remains to be answered of course is the place of interested third parties as regards these principles and models. Within that question are especially these two as regards seriously disabled newborns: who is the physician's "patient", the newborn or the parents, or both? Should the wishes of parents regarding treatment prevail? The resolution of these questions, and the responses provided by the various branches of bioethics and the law will have to await subsequent chapters.

There are still other important principles which play a role in philosophical bioethics, though we cannot and need not deal with them in any detail at this point. One of these principles is that of <u>respect for persons</u>. This is an essentially Kantian principle, and is sometimes used as the principle underlying and justifying those of autonomy and self-determination referred to above.[141] This principle in effect means that man is not to be used as a means to serve other ends.

Another principle is that of justice. It is sometimes proposed as a necessary balance between on the one hand the more individualistic or consequentialist principles such as autonomy and beneficence (the latter understood here in its narrow sense of focusing on benefits and harms to the individual patient, not the larger society), and on the other hand utilitarian uses of beneficence in which all benefits and harms to society are calculated in terms of aggregate net benefits, subordinating the individual to the interests of society.[142] Justice in bioethics is applied to a wide variety of issues involving the fair and equitable structure and operation of institutions. Among these issues are the just distribution of and access to health care, and just decision-making procedures and processes about expenditures and treatment. There is very great interest and voluminous writing in philosophical bioethics concerning the meaning and implications of justice in health care and treatment decisions, much of the interest undoubtedly stimulated by the influential work on justice by John Rawls.[143]

There are of course on-going debates in philosophical bioethics as in ethics generally about which of these or additional principles should rank the highest, which is the most fundamental, whether one or more are in reality sub-divisions or offshoots of a single principle, and which principles are really necessary to adequately address moral issues. Though the principles indicated above tend to emerge the most often, the answers and arguments as to their priority, number and necessity are many.[144] And depending upon which principle predominates in a particular ethical theory, the answers or directions provided on a specific issue will tend to be different.

A last point to be noted about principles in the philosophical context is the sort of characteristics they must have to qualify as principles. On this issue as well there is a fairly wide spectrum of views. Two in particular tend to be generally favoured - universality and publicity.[145] By universality is meant that a principle can apply to everyone. By publicity is meant that one should be able to publicly and openly express it if it is a true principle.

Not only do the principles themselves each imply a different emphasis looked at separately or in different combinations, but the particular decision-making <u>theory</u> or method in which they are used and combined will also of course colour the outcome. The three most commonly used ethical theories, deontological ethics, consequentialist ethics and utilitarian ethics all have their proponents in bioethics as they do in ethics generally.[146]

Chapter V: The unique nature and contribution of theological bioethics

In view of what has preceded then, what if anything is unique in bioethics about its theological branch, and what can it contribute to bioethics in general and newborn treatment policies in particular? Does theological bioethics provide and use theories or methodologies for doing ethics which are not to be found in secular bioethics? Do we find in theological bioethics a content in terms of principles and directions substantially different from that of secular bioethics? To the second question our answer is, no; to the third question, yes and no.

As for theories or methodologies of doing ethics, one could reply that an obviously unique feature of theological bioethics has to do with the role of conviction, faith and revelation found in theological bioethics alone. Perhaps so, but we choose to deal with those aspects below under the "content" heading. In the area of methodologies or ethical theories there seems no reason to insist that essentially the same methods, theories and emphases used to reason ethically in philosophical bioethics are not to be found in those working from the theological perspective. In terms of methodology, a deontologist of a theological persuasion would go about the business of trying to solve an ethical problem by applying a principle or rule to various alternative actions in essentially the same manner as a deontologist working from the philosophical perspective. To anticipate our next point regarding content, one could add that they are very likely to be using essentially the same principle or rule as well - for example justice, or the sanctity (or dignity) of life. In terms of particular bioethicists, one could undoubtedly label Paul Ramsey as a deontologist.

The same is true for example of the ethical theory of utilitarianism. One could label Joseph Fletcher an "act-utilitarian" in view of his positions summarized above. Insofar as act-utilitarians are those who judge every action according to whether it will promote the general happiness, if we but substitute what Fletcher calls agapé for general happiness, he would seem to comfortably fit the description of this ethical theory. Whether theological or philosophical, the act-utilitarian will follow essentially the same methodology in solving an ethical problem - identify the alternative solutions, predict the consequences of each, determine a value of happiness (or agapé) for each solution, and choose as the morally right solution the alternative with the highest value of happiness (or agapé).

1. Its nature - from theory to story

What then of content? Is there a material distinction to be made between Christian ethical principles or moral demands, and those of secular bioethics discernible by reason? As already suggested above, if what is meant is what McCormick refers to as essential ethics (demands thought to apply to all persons as persons rather than as Christians)[147] then a negative answer is justified. It is not just a Roman Catholic position insisted upon by Thomas Aquinas and others since, but is affirmed as well in Protestant theology and bioethics. Gustafson for example writes:

> 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 needed 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 action and the ethical thought of persons who find theology to be a meaningless intellectual enterprise.[148]

Writing of the sanctity of life, Ramsey writes that he does not doubt that there can be a truly humanistic ethic which, "acknowledges the awesome claims and entitlements of another human life simply because he or she is a human being. Where I would be inclined to say the 'sanctity' of human life, the reader may choose rather to say the 'dignity' of human life".[149] That there should be this identity between Christian morality and secular, humanistic ethics should not be surprising. Whatever else Christian morality might also be or include, it begins by accepting what is human in all its dimensions.

But what then is, if anything, the special feature and contribution of theological bioethics? First we shall consider the special feature or nature of Christian ethics and bioethics, then its contribution. That unique nature or feature is to be found in the <u>way</u> it views and underlines what it is to be truly human, what in the human requires valuing and protecting and what moral attitudes and actions follow from the Christian experience. The experience of God and Jesus Christ is not so much a question of new content added to morality, as a special outlook, commitment, dimension, and seriousness.

The Christian experience provides additional and prior reasons and motivations for being moral, rather than a whole new morality, so that for the serious Christian (as undoubtedly for those of other religions) moral acts are at the same time religious acts. That does not imply that persons who do not share that experience are not themselves moral and do not have their own formative and motivating experiences and stories whether religious or otherwise, only that, "to experience the reality of God with special clarity through the Christian story, however, has, and ought to have, the consequences of nourishing (if not creating) loving, hopeful, and faithful dispositions in Christians".[150]

It is then arguable that there can be essential identity between the moral principles and general moral duties promoted by theological ethics (and bioethics) and secular ethics (and bioethics). But the difference of interest to us lies in the motivating power of the particular experience and stories which illuminate and expand those principles and duties, an experience and stories which both reinforce the morality shared with others, but which also challenge Christians to go beyond what reason and humanism alone can oblige.

The place of story, narrative or event in the Judeo-Christian tradition and in the lives of Christians helps to explain what is distinctive about Christian ethics and bioethics, and therefore merits at least summary attention here. The Protestant ethicist Stanley Hauerwas has written with much insight and persuasion on the role of story in ethics, particularly in Christian ethics.[151] That position is essentially the following:

> ... even though moral principles can be justified without reference to God, how they are accounted for still makes a difference for the meaning of the principle and how it works to form institutions and ways of life that may have practical importance. To be sure, Christians may have common moral convictions with non-Christians, but it seems unwise to separate a moral conviction from the story that forms its context of interpretation.[152]

It has of course long been an insight of biblical theology that Judeo-Christian morality is not primarily about moral precepts or rationality, but about events - God's divine, salvific and loving activity in the past and the present, establishing a covenant with his people and calling for responses in kind. It is acknowledged by many Christian ethicists that this fundamental fact is too often overlooked in Christian ethics.[153] The Decalogue for example would be meaningless apart from its motive and context - the event and story of the covenant. The Book of Deuteronomy attempts to recapture the covenant made with Moses and to make moral obligation once again a matter of recalling that story and responding in obedience motivated from the heart.[154] The same theme of responding in loving obedience to what God has done for his people, in the old covenant, through Jesus Christ historically and in the present, runs all through the New Testament.[155] Both testaments recount story after story not only of what God did but of how individual real people responded, why they did as they did, how they failed and how they succeeded. The people in those stories are people with their human dimensions, contradictions, virtues and failings left more or less apparent despite successive edits and interpretations in the biblical text.

A serious Christian who is nurtured on those narratives of divine actions, human responses, obedience, disobedience, sin and virtue, combined with the stories of saints and sinners in subsequent history and recent times, will confront and respond to the moral challenges in his own life and society in large part (though not only) by applying lessons learned from those stories about (Christian) heroes and sinners. The way he responds to his moral challenges and what he perceives to <u>be</u> the moral challenges, constitute his own personal story. As well, his moral attitudes and vision of what matters most about life, other humans, and so forth, because of the special power of narrative (as opposed to only explanation, precept or reason) will tend to exist at the deepest levels - those of belief and conviction, combined with a large quotient of the personal given that we all have our personal stories.[156]

But, as Burrell and Hauerwas have convincingly established, contemporary ethical (and by inference, bioethical) theory is at considerable odds with (or at least does not account for) those insights about human and Christian experience:

> Thus the hallmark of contemporary ethical theory whether in a Kantian or utilitarian mode, has been to free moral behavior from the arbitrary and contingent nature of the agent's beliefs, dispositions and character.... Ethical rationality assumes it must take the form of science if it is to have any claim to being objective.... Many thinkers have tried to free the objectivity of moral reason from narrative by arguing that there are basic moral principles, procedures or points of view to which a person is logically or conceptually committed when engaged in moral action or judgment. This logical feature has been associated with such titles as the categorical imperative, the ideal observer, universalizability, or, more recently, the original position. Each of these in its own way assumes that reasons, if they are to be morally justified, must take the form of judgments that can and must be made from anyone's point of view. All of the views assume that "objectivity" will be attained in the moral life only by freeing moral judgments from the "subjective" story of the agent.[157]

We cannot and need not point out all the limitations of that view from the Christian perspective, but some brief observations are in order to more precisely identify the distinctive nature of Christian ethics and bioethics compared to contemporary philosophical ethics (or what Burrell and

Hauerwas refer to as "the standard account of rationality"). In the brief summary that follows we rely largely on that analysis of Burrell and Hauerwas already referred to.

To divorce moral duty from tradition, narrative and personal story is undoubtedly related to the tendency in our times to focus on "quandary-type" problems - those in which there is a conflict of choices, and thus to make of ethics a form of decision theory.[158] By focusing on this kind of problem (and that of treating seriously disabled newborns is obviously such an issue), the impression is created that we can justify judgements and decisions more or less independently of the agent judging. It is not at all a question of a particular individual (or community) deciding, with particular convictions and personal (or communal) story - those reasons and beliefs are unimportant and even misplaced according to this view. In other words, that account and perspective:

> simply ignores the fact that most of the convictions that charge us morally are like the air we breathe - we never notice them, and do not do so precisely because they form us not to describe the world in certain ways and not to make certain matters subject to decision.... These are not matters that we need to articulate or decide upon; their force lies rather in their not being subject to decision. And morally we must have the kind of character that keeps us from subjecting them to decision.[159]

In focusing almost exclusively on problems, and decisions, the "standard account" deals inadequately or not at all with character and its formation. It is not only in the context of decisions that our character or dispositions are important, rather it is character,

> inasmuch as it is displayed by a narrative, that provides the context necessary to pose the terms of a decision, or to determine whether a decision should be made at all. We cannot account for our moral life solely by the decisions we make; we also need the narratives that form us to have one kind of character rather than another.... As our stories, they will determine what kind of moral considerations - that is, what reasons - will count at all.[160]

Making rationality itself the only judge of moral conduct fosters an erroneous explanation for moral conflicts, and thus obstructs efforts to resolve them at the relevant level. Contemporary ethical theory tends to assume that moral disagreement necessarily involves differences about a moral principle (e.g. all life is sacred) or about a question of fact (whether the fetus or the newborn is human life). But in reality those for and against abortion or euthanasia for example, very possibly disagree more because they have quite different perceptions not about principles or facts but about the notion "abortion" or "euthanasia", a difference dependent upon different narratives or stories. Regarding abortion for instance those stories might be about the place of children in my life, rather than about a principle such as the sacredness of life.[161] Attempts to find common ground would then be misplaced and non-productive if they focus simply on whether abortion for example is "right" or "wrong".

It is worth noting that philosophers themselves are in some cases well aware of the limits of rationality in respects similar to those discussed above. James Rachels for example is prepared to admit that the "caring" factor is too seldom considered in ethical disagreement, and that such disagreements tend to be attributed to a failure of rationality on the part of one or another person while it might simply be that they care about different things and are different. He acknowledges that, "... for anything to count as an ultimate reason for or against a course of conduct, one must care about that thing in some way. In the absence of any emotional involvement, there are no reasons for action".[162]

2. Its contribution

Becoming more specific, what then can be the unique contribution of theological bioethics to bioethics and bioethical policies? As already suggested, that contribution will not be new in content, but is more a question of outlook, interpretation and conviction about what counts, what matters, about human beings. Theological bioethics does not have inherently within it all by itself detailed moral policies for every specific biomedical possibility, particularly not in our pluralist society. But it can contribute its collective insights and reminders based upon its responses to new biomedical challenges in the light of the Judeo-Christian events and narratives.

A. Respect for life - the mentally handicapped

First on this list of attitudes and convictions would undoubtedly be a respect for the sanctity of life. Having already indicated above the centrality and theological reasons for that Judeo-Christian attitude, particularly the narratives of creation and salvation, we need not do so again. But whether the issue is newborns or the aged, the conviction that all human life is to be respected and loved, and that we may not unjustly endanger or take life because it is God's, stands as a reminder and accusation against all attempts to treat persons functionally or as means to some professedly good end. In this regard, Judeo-Christian bioethics is not as bound as is philosophical bioethics to confine its moral reflection to the existing social framework and structures. Whereas an exclusively problem-oriented ethics assumes the existing societal framework in which the problem arose, and so tends to be a conservative force,[163] that need not be so for an ethics which need not take the existing world and scheme of things as a given.

Theological bioethics is thus free (and even called to) sometimes play the role of prophet by uncompromisingly and insistently reminding believers and others that if the threat to life or lives requires structural changes and re-ordering of societal priorities, it should be done.

An instance of that may well be the mentally handicapped, whether newborns or not. Arguments are sometimes made (and, as we shall see sometimes incorporated or implied in policies) that our society cannot afford to treat and care for the mentally handicapped because that imposes limits on the quality of life of others not so handicapped. But the serious Christian or Jew would respond that if there does indeed have to be a choice, let us change the priorities of society to accommodate the care and treatment of our mentally handicapped brothers and sisters. Arguably the real problem is not whether we should care for them (which should not even be at issue or require a decision) but how we can change our unjustified societal expectations of an increasingly better way of life for the majority when that way of life is bought at the expense of a few of its weaker members.

For the Jew or Christian in this debate the position seems clear enough. The vision of life they have to offer is based on God's call to care for and love the sick and the weak as God loved us. That includes going beyond the bounds of (though not against) reason alone since that call, demonstrated most vividly in the event and narrative of Jesus, involves being perfect as the Father is perfect. This will necessarily sometimes involve going beyond the humanly possible and even the humanly desirable, since it would no doubt cost us all more in terms of money, effort and care. But there is an inescapable note of radicalism in this perception and attitude, one which cannot avoid putting those who act on it and urge society to act on it in a state of tension with the rest of society. In the final analysis the one inspired by the Judeo-Christian tradition can only say:

> I cannot deny this care for my retarded brother even in the name of creating a better world for all "humanity", or for "my already existing family". A world so created or a family so sustained cannot be "better"; it deafens me to the call of humanity this one child offers me.... The Christian's duty is to care for the weak, and no limits can be placed on that demand ... the Christian's care for the weak embodies no grand humanistic vision, but only the idea that regardless of its accomplishments, no society that fails to care for retarded will be worthy or humane. It is just this kind of vision that exposes the sinful and power-hungry pretensions we hide behind our claims to serve others in the name of humanity. No such humanity exists except as it is found in a child who must struggle to speak his name.164

At the same time Christian experience and conviction can contribute by challenging the assumption sometimes found in medicine and elsewhere that there is no good beyond what we can accomplish here and now in this life, and that life is an end in itself. There are in this assumption the seeds of an idolatrous attitude to life. Divorced from a theological context in which God, not man, is acknowledged to be the lord of life and death, that assumption and attitude tend to follow readily, and feverish efforts to sustain physical life at all costs displace the traditional Judeo-Christian outlook that we are not obligated to protect life as if it were an end in itself. Idolatrous reverence for life is no part of respect for the sanctity of life, for, in the words of Barth, "Life is no second God, and therefore the respect due to it cannot rival the reverence owed to God".[165]

B. Attitudes - openness, and awareness of finitude and sinfulness

Still other insights which Christian experience and tradition is able to contribute to bioethical debates and policies are more in the nature of attitudes than content. Here we will suggest only two, both of which flow from the earlier descriptions of the highlights of theological bioethics. One of these attitudes is what Gustafson calls an "attitude of openness".[166] As with other outlooks, themes and attitudes referred to here, this one is not necessarily exclusively to be found in the Christian tradition and consciousness, but it is to be found there loudly and clearly. We agree with Gustafson as to its centrality and meaning:

> The attitude of openness coexists with the attitude of respect: whereas respect curbs openness from becoming a license for heedless interventions and explorations, openness keeps respect from becoming dogmatic and idolatrous.[167]

The attitude of openness could be said to include under its umbrella at least two related elements central to Christian morality. One involves the notion of man as "co-creator" or "co-actor" with God, accepting his God-given responsibility to shape this world, responding to the new and evolving conditions and challenges, in our case in the arena of biomedicine. From Christian tradition and experience we can deduce that the unfolding of creation with its new conditions and challenges is not haphazard or accidental, but the God who creates and preserves life also creates the new possibilities calling for new and creative responses from men. We do not necessarily agree with Gustafson that these responses involve, "a reordering of accepted values",[168] or that new possibilities for the larger community should be pursued even at the expense of irreversible harm to individuals.[169] It ought to be possible and is desirable in our view to respond to those new conditions and possibilities in faithfulness to basic Judeo-Christian and humanistic values, and without buying technological and other advances at the expense of individuals. Clearly traditional values must be further refined and balanced to meet new challenges and complexities, but it is doubtful whether new conditions seeming to call for a "reordering" of essential values or threats to individuals for the sake of the larger community really are God-created conditions and calls.

An attitude of openness in accepting the role of "co-actors" in God's creation is directly relevant to our issue of treating disabled newborns. To establish that this attitude and conviction is indeed anchored in the Judeo-Christian tradition is to refute those who feel that making life and death treatment decisions is necessarily "playing God". On the contrary, such decisions and interventions, if respectful of life and that individual life, are not instances of "playing God", but of carrying out one's God-given mandate.

Another and related element which could be included in this attitude of openness has to do with the "natural law". Openness to on-going creation and new possibilities forces us to escape the confines of an unchanging and fixed natural law view of man, the world and moral conduct. Macquarrie acknowledges the enduring legitimacy of the concept of natural law, but adds:

> More and more, man takes over the direction of "nature" - both external nature and his own nature, that is to say, those elements of his being that are simply "given". As this process goes on, it is clear that "natural law" ... must have flexibility. What might have been against natural law at one time may not still be against it as man, fulfilling his destiny, reshapes his own "nature" or develops it or reduces the area of the "given" by bringing more of his being under his conscious responsible will.[170]

Another attitude with strong roots in earlier and contemporary Judeo-Christian tradition and experience, one highly relevant to bioethical debates and policy-making, is one we could call awareness of our limitations, finitude and sinfulness. This attitude implies great humility and care in the face of the serious risks involved in attempting to respond to biomedical challenges such as human experimentation, genetic engineering or treatment decisions for seriously disabled newborns. We are, after all, finite human beings, our judgement and powers of prediction and prognosis are both limited and clouded by sin. That being so we are capable both of being wrong and of deluding ourselves - of convincing ourselves for example that a proposed course of action or policy is for the benefit of the patient or subject involved, whereas it may in fact be consistent only with our conscious or unconscious wish to rid the world of suffering, or improve the genetic or social quality of the lives of others, or some equally grand but questionable vision.

It is an attitude which includes self-criticism,[171] a readiness to question and probe both our motives and our facts given the serious, widespread, sometimes fatal and long range consequences of decisions and directions being contemplated. Self-criticism and caution imply a readiness to acknowledge that no one of us, nor any single tradition or body of experience, Judeo-Christian included, can alone provide all the moral insight and information needed. No matter the majesty, grandeur and age of the Judeo-Christian tradition, (or the narratives and traditions which form and influence others), it is nevertheless mediated through the experiences, interpretations and language of finite, imperfect and culture-conditioned human beings. That being so, there will always be a degree of uncertainty about how particular principles and moral precedents should apply to new biomedical complexities and problems, and a constant need to re-examine, re-experience and re-phrase. There is no room for infallibility, pride or complacency in that exercise, but much room for humility, caution and self-criticism.

C. Contributing to policies in a pluralistic context - three models

If theological bioethics has distinctive features and something to contribute to the understanding of biomedical issues such as ours, the next question is exactly how have those experiences and insights contributed to and been accommodated within policies, and how could they best contribute? The type of policy of interest to us on the subject of seriously disabled newborns will include in the first place "policies" in a somewhat wide sense - the policies which we can construct from the actual practices and views of physicians (the subject of Chapter VII). Secondly, they will be policies or guidelines in the narrower sense, specific sets of proposed or adopted criteria intended with varying degrees of obligation to guide or regulate decision-makers, including those proposed by bioethicists, courts and legislatures (the subjects of Chapters VIII and IX).

In the course of the next chapters we will be addressing essentially the same questions to all those forms of policy, namely, what contribution, if any, has the theological perspective made to those attitudes, practices and policies, and how, if at all, have they accommodated that perspective (or better, those perspectives), given the pluralist context of our society.

In this section of this chapter, our aim is simply to identify in very general terms the options available regarding the role of the theological perspective in any neonatal treatment policy, without at this stage distinguishing between the types of policy. Also to be suggested here will be a preferred option, one which is arguably the most consonant with the dynamics and insights of theological bioethics. At this stage those options will only be sketched - it remains to the next chapters to determine whether that proposed approach is workable and to what extent if any it can already be discerned in policies.

We submit that given our pluralist context, those interested in having the theological perspective, or a particular theological tradition, incorporated into a treatment policy, have essentially only three routes to follow. In each case picture a group of people sitting around a table with the job of designing a treatment policy.

i) In this model those around the table are all members of a particular religious tradition. Their mandate is to design a policy or guideline which is explicitly and more or less exclusively theological in expression, argument and treatment options, one intended to operate in a religious hospital or institution or association. The resulting policy essentially only repeats some traditional Christian principles and identifies the moral and immoral treatment options, but does not attempt to come to grips with some of the truly complex and perplexing ethical dilemmas in treating newborns, nor does it allow for the fact that many of the patients and some of the staff of that institution are not members of that particular (or any) religion.

ii) In a second model those around the table include a theologian, a philosopher, physicians, lawyers, and hospital administrators. The hospital has no religious affiliation, and members of the staff as well as patients represent a mix of religious, non-religious and cultural backgrounds. The theologian attempts to persuade the others to adopt a policy incorporating his own particular theological perspective including the guiding principles, detailed criteria and indications as to which treatment options are morally acceptable and which ones are not. Meeting resistance, he criticizes the others for their "secular humanism" and for failing to respect the positions and rules of his particular church.

iii) In this third model, a similar group is around the table. In this case the theologian participates actively in shaping the treatment policy and carefully articulates for the others the insights and convictions of his religious tradition concerning the meaning and value of human life including the significance and implications of caring for the sick. He also indicates to the others in what respects other religious traditions differ. But he does not feel he has a corner on all the moral insights, or that his religious tradition provides all the answers. He represents a definite point of view but sees himself as a partner participating in a common endeavour with others. He knows he has much to learn from the physicians and others about the medical technicalities, complexities and possibilities he must respond to, but also much to learn from their ethical insights and convictions, and those of the philosopher as well. He listens as much as he speaks, and when he speaks he does not preach, accuse others of moral ignorance or insist that his convictions and attitudes are the whole truth.

> He and others strive for as much moral consensus as possible, attempting to include in the policy as much ethical groundwork and moral substance as possible, and to provide as much direction as they can agree on for the complex dilemmas and conflicts which physicians and parents and institutions face. But they also leave as much room as they can within the moral and legal parameters agreed upon to accommodate the different views and convictions of the patients, physicians and families of various religions and other traditions making up the pluralist mosaic.

Those descriptions of three possible stances a theologian could adopt towards the making of policy are of course somewhat simplistic and overdrawn. Obviously the reality is more complicated and one could no doubt add more models to those three. But hopefully the three models nevertheless illustrate some of the major role choices to be made by theological bioethicists regarding the place and function of theology. Our own preference is for the third option, as may have been apparent to the reader. In view of that choice, further explanation and evaluation is in order.

The description of the first model is not meant to be pejorative about the role and importance of policy-making in religious institutions or associations. The commitment and values of those who practice in that context can of course be admirable, and equally the policies and practices can be faithful and sensitive reflections of the theological perspective of that religious tradition. But the pluralist society is not in this option a primary consideration - in theory at least policies in that religious context can assume such a large degree of identity in the stories which nourish their faith and in their shared moral values and conduct, that they can skip over the most difficult (and yet creative) aspect of moral ~~policy-making~~, that of participating with others of various religious and secular "persuasions" in the task of finding common ground yet respecting and incorporating into policies different experiences and views. In fact so much can be shared in a religious institution that explicit policies or guidelines are often felt to be not necessary - they are for obvious reasons most desired or desirable in contexts where there is most disagreement about assumptions, values and moral conduct. That there is that degree of agreement in those religious contexts is surely not a fault or drawback - quite the contrary. But given our interest in policy-making in a pluralist context, this will not be the model of most interest to us.

The second option as well is something of a construct rather than a likely real-life reality. One can hardly imagine a theologian actually being quite that heavy-handed and critical in that pluralist context. Yet it does allow us to pinpoint a particular attitude which is at least occasionally tempting for a theologian in a pluralist context. But not only is that attitude counter-productive, but also a misreading of the role and place of the theological perspective.

We may profitably apply at this point the labels used by Gustafson in discussing the social roles of the theologian - those of preserver, prophet and participant.[172] Borrowing in some respects from the typology of H. Richard Niebuhr, Gustafson suggests that as prophet the theologian would feel called upon to preach loudly against the evils of his time, to insist upon the absolute will of God, to withdraw from contact with those judged to have forsaken the true path, and to be more or less incapable of coping with the reality of a pluralist society or participating with others not of his conviction as an equal in moral discourse. This model of the theologian as prophet would seem to fit our theologian in the second model. For essentially the same reasons implied by Gustafson, we reject that approach as inadequate in our context. There are of course important and needed elements in the prophetic role of the theologian - there will be times in any context when evil should be clearly and loudly railed against. But if that is all there is, or if it stems from self-righteousness and a sense of infallibility, it is likelier to close doors to understanding than open them.

The third model is our preferred one because it seems to most reflect what theology and theological bioethics and the theologian in our pluralist society are or should be. The theologian is one who reflects with others on the meaning of human existence, on God's activity in the world and the values and moral conduct which accord with God's will and activity, he is willing to work with others to shape the human processes and institutions which can promote or impede the dignity of man and moral conduct. Among those processes are most certainly those involved in biomedicine, and among those institutions are most certainly hospitals and neonatal units.

That third option is close to what Gustafson calls the "participant" role of the theologian, the one he endorses as the most fitting for our times:

> The participant stands between the types of prophet and preserver; in another sense it draws elements of each and moves beyond them. The participant is wedded neither to the condemnation of the existing state of affairs, nor to whole-hearted support to them.... He is actively involved in the shaping of events and in the development and reordering of institutions.... He represents a point of view about what the primary purposes of human existence in community and history are, about what the qualities of life ought to be.... The participant is one partner among many in the human conversation that will give some determination to the ways in which men use their technical and political powers ... he is oriented toward policy and toward actions - those of persons and of centers of power, established and nascent - that give direction through purpose as men move toward God's future.[173]

In this model the theologian or theological bioethicist recognizes that in our pluralist society moral consensus on every aspect is beyond us. We may well agree on some basic general principles such as the sanctity or dignity of life, and that would of course be a crucially important starting point and gain. It is at least likely for example that the philosopher sitting at that table with the theologian might agree with that principle though for humanistic rather than theological reasons. After all, some philosophers do attach a very high and normative value to the inherent dignity of man. Shils for example writes:

> The chief affirmation of the proto-religious '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 acknowledgement of sanctity.[174]

Whether philosophical or humanist adherence to the sanctity of human life as "inherent" dignity will ground for those who profess it the same concrete obligations and prohibitions as for those who profess a theological meaning to that principle, that of "alien dignity", is another matter. Those around that "pluralist" table may well, after much discussion and learning from one another, agree upon some concrete demands at least of a general nature. There are after all many general principles and duties in the nature of what McCormick calls "essential" ethics (those which apply to all persons as persons, not as Christians) which are discoverable by reasoning. Fair and sympathetic consideration of opposing positions could go a long way towards consensus. As another philosopher (correctly) reminds us:

> There is still in any case in our own society a very high degree of moral consensus in spite of the talk about a "plural" society. This is easily over-looked because attention is concentrated very naturally on points of contention. That we should relieve pain, respect life, tell the truth, preserve confidences, give weight impartially to competing interests, these and many other principles are not in dispute. Moral philosophers may disagree as to what is their rational basis, and they may be subject to different interpretations, but philosophers have to accept them as given if they are to take morality seriously at all.[175]

All that is undoubtedly so, but the truly difficult and sometimes overwhelming task is to move beyond a certain level of abstraction to specific and concrete moral parameters and demands. To argue the duty to respect life is an important beginning, but how far should that go and what does it mean exactly in concrete moral dilemmas? How hard should we fight to save a disabled newborn's life? Does respect for life prohibit euthanasia? Even some theologians would answer in the negative - e.g. Joseph Fletcher and Daniel Maguire. We might all agree that the principle of truth-telling is beyond dispute, but does it oblige us to always tell parents of seriously disabled children the whole truth about their child? Medical practice at least indicates a wide range of views about that. The obligation to relieve pain may also be beyond dispute, but does that extend to mercy-killing as well?

There will then be differences around the policy-making table about the exact moral parameters for a policy and the specific moral obligations and rights which follow from the principles. Not only because theologians and philosophers are likely to disagree, but because theologians of various traditions (and even in the same tradition) will disagree. This is not necessarily regrettable - it may even be healthy in some respects but it is at least a fact of present-day life. After all the reasoning, listening and learning is over, there remains the fact discussed above, that people care or believe about different things, and in different degrees. We are shaped to some degree by different experiences, narratives, stories.

Nor can those attempting to hammer out a policy overlook the fact that it is meant to apply not only to them but to the entire staff of that institution or unit, and must take into consideration parents and families of the newborns as well as other interested parties. Policies must obviously be written with that larger group, and their predictable differences in vision of life and perceptions of concrete moral duties, in mind.

In conclusion then, there are two dangers, two extremes to be avoided in policy formulation about this and similar bioethical issues. One is that of remaining at too general a level of abstraction, simply stating first principles (e.g. the sanctity of life) with few specifics as to where that principle should lead in caring for newborns. Such a policy would be relatively easy to formulate but of little or no help and guidance to anyone faced with the typically complex conflict of desirable goals in concrete cases. But the other danger would be to be so specific and detailed that no space is left for morally (and legally) legitimate differences based at least in part on different theological or religious traditions and convictions. In a pluralist and largely secular society it would be a violation of one of the basic convictions of democratic principles not to respect, insofar as possible, the different religions and other perspectives and traditions which have sometimes differing views and stances on these matters.

Ideally and necessarily then such policies will include as much of a substantive and specific nature as possible, but at the point of excluding irreconcilable positions will shift to include procedural considerations as well. At that point the concern will be, not, what specifically should be decided if faced with this concrete case and conflict, but who should contribute to the decision or make the decision (parents? physicians? courts?) and according to what procedure and criteria. Or put somewhat differently, the special contribution of secular bioethics or philosophy will be that of ensuring what it can best contribute, that is a largely neutral framework ensuring freedom, fairness, toleration and respect for various religious and other traditions within that framework.[176]

PART TWO. EVALUATING DISABLED NEWBORN TREATMENT POLICIES IN MEDICINE, BIOETHICS AND LAW

Chapter VI: The ethical tests and the medical data

1. The ethical tests of policies

In this second part of the thesis our goal is to apply some of the findings of Part One to particular treatment policies already in effect or proposed by medicine, bioethics and law. The emphasis will be on theological bioethics, in that the elements special to that perspective will be highlighted in the tests applied and contribution examined. But since, as already established, the Hippocratic and secular (philosophical) perspectives share much in common with that of theology in this matter, it is neither possible nor necessary to draw unbroken lines between the contributions and roles of each. It will in fact be one of our concerns to test the policies selected as to whether the special contribution suggested above for secular bioethics is realized, namely that of providing a largely neutral framework promoting fair procedures and respect for the stances of various religious and other traditions. In our pluralist context such a framework has become imperative, and as indicated, is a value promoted by the theological perspective itself.

The actual policies chosen for study within each of the three disciplines - medicine, ethics and law - are of course only some of the many possible candidates. Clearly for example, the treatment policies of Doctors Lorber, Freeman and Zachary are by no means the only ones we could have chosen. But as it happens, they and their supporting arguments (especially the first two) are the most elaborate and detailed medical policies, and they do represent well the major options and alternatives. The same is true for the bioethical newborn policies selected - those of Fletcher, McCormick, Ramsey and the Sonoma conference. As for the legal policies selected (in the form of a number of court decisions), they are of course only the tip of the iceberg, but each of them allows us to focus on one or more aspects central to the legal stance on treating newborns, and together these cases provide a fairly comprehensive picture of legal priorities and policies regarding disabled newborns.

The first task is to summarize what we proposed in Part One as the special characteristics of theological bioethics, which will now serve as the tests to be applied to the various criteria and approaches which physicians, bioethicists and courts propose for resolving these treatment dilemmas. Since, as already indicated in Part One, there is a fairly wide range of views on some points even within theological bioethics, choosing the priorities which shall serve as our tests is necessarily somewhat subjective and a certain level of generality is inescapable. Yet, as also noted above, there is as well a degree of consensus or at least a "majority view" on some important priorities in the theological perspective (for example the repudiation of active euthanasia, and the focus on the protection of those who are the weakest and most vulnerable), and especially those points are justifiably included in these tests. In some other cases the priorities or tests have been left sufficiently general to accommodate a range of positions or formulations within them. It is one of the goals of these chapters to determine the particular theological flavour or bias (if any) implicitly or explicitly endorsed by various policies.

The tests and priorities will focus mainly on substantive ethics as opposed to procedural ethics. There are of course many extremely important issues involved in these policies which are essentially procedural in nature, especially the "who decides" questions. Involved in this category of issues are for example the role of committees, the extent of medical consultation, the decision-making authority of parents, and who should contribute to the fashioning of policies. But attention in this thesis will be directed primarily to what could be termed the substantive matters, both of content and orientation. This self-limitation was imposed for two reasons. One is that the more unique contributions of theological bioethics are arguably not about procedural matters. While those issues are given attention by theological bioethicists, for the most part their insights are not noticeably different from those of secular bioethicists. Which means that tests derived from theological bioethics regarding the "who decides" questions would not in most respects be noticeably distinctive. Secondly, there is the simple matter of limited space and the danger of including too many issues and blurring the focus. Procedural matters comprise a special subject worthy of a separate thesis.

At the same time some attention will be directed to one issue which is largely procedural in nature - that of parental consent and wishes. The justification for that inclusion is simply that the role of parental wishes in our issue is not in reality totally separable from the more obviously substantive matter of the sanctity of individual life. The scope allowed to parental wishes by a given treatment policy is arguably a strong indication of the degree of commitment to the sanctity of individual newborn life. For example, to propose that parental wishes should be decisive in life-prolonging treatment decisions whatever the medical indications, is arguably to assign correspondingly less importance to the inviolability and sanctity of that disabled newborn's life.

We turn now to the theological tests or priorities which will serve as our measuring rods of the contributions and role of bioethics.

A. The sanctity of individual life

As already established in Part One, the view that life is sacred (or at least possesses some such quality) is not in all respects unique to theological bioethics. The Hippocratic tradition for instance clearly highlights respect for patients, a respect which includes doing everything possible to help the patient and avoid doing harm. But that tradition, including the Hippocratic Corpus and modern medical codes of ethics, provides us with no theory of values behind the exhortations to respect the patient. As a result we find in that tradition no assertion that human life is sacred. More importantly from the perspective of policies and codes, because there is no theory of values, there is no guidance provided as to the scope and application of the obligation to respect the patient. There is no concrete indication of how far respect for life obliges one to go in saving and prolonging life, and when respect for the patient permits cessation or non-initiation of treatment. Put another way, the lack of a theory of values in the Hippocratic tradition means that the ethical obligations such as respecting and helping the patient are stated as absolutes, with no real guidance provided as to resolving and balancing conflicts in values, interests and principles.

As for philosophical or secular bioethics, we have already noted that a humanistic ethic can sometimes ascribe to human life an inherent sanctity or dignity. In this perspective life is sometimes said to be sacred, not because it is created by God or is a manifestation of a transcendent creator, but simply because the experience of life and the fear of its loss leads man to "stand in awe before his own vitality".[177] A particular expression of this respect for the inherent dignity of life in philosophical ethics is one shared to some degree with the Hippocratic tradition (though considerably more evolved in the former), namely the principle of beneficence. According to that principle one should seek the greater balance of good over harm in caring for patients. Though an often competing principle in this tradition is that of autonomy, we noted earlier that in the case of newborns the autonomy principle and model is hardly relevant. In secular bioethics it is the principle of beneficence with its calculations of benefits and harms which applies.

But we have argued that theological bioethics generally understands the sanctity of life imperative as something other and more than just the rational calculation of benefits and harms, attainable equally (in the view of secular ethical theory) by all reasonable and objective persons. It is this something other and more which should be captured in this first test of policies and criteria. The uniqueness of the predominant theological stance on the sanctity of life is largely that of its special motivation and conviction, but for that very reason it is in part at least a matter of content or scope as well. Nurtured by the Judeo-Christian events and narratives (and not just universalizable principles) the serious believer does not simply approach the sanctity of life principle (or others) in an objective, logical manner, detached from his beliefs and character. Rather he has and shares a conviction that not only is all human life to be respected and loved, but that this respect and love will go beyond what is reasonable and desired by human standards alone.

The special insight and outlook which informs the reasoning of the believer can be variously expressed· it resists all attempts to treat people functionally or as a means to some other end; it holds that though the sanctity of life principle is abstract, it is not meaningless, and means that life is precious, to be respected, protected and treated with consideration; it assigns the highest priority to the protection of the weakest members of society, such as the seriously mentally disabled newborn; it goes beyond the bounds of reason alone in caring for the weak, by preferring to change existing social structures and priorities by incurring more costs and burdens on the healthy, than to sacrifice a weak and helpless person to a better quality of life for those who are healthier. All these elements make up what is or should be the special contribution of theological bioethics to newborn treatment policies in the matter of the sanctity of life, and are therefore the elements to be sought for in the policies to be examined.

B. The exclusion of euthanasia as an option

As indicated in Part One, not every theologian would exclude mercy-killing under all circumstances. Both the Roman Catholic ethicist Daniel Maguire, and the Protestant ethicist Joseph Fletcher argue that if allowing to die can be ethical, so too can euthanasia or mercy-killing since there is no ethical difference between commission and omission. The purpose, (they argue) is the same - death. But as indicated, they are in the minority in so holding, most theologians and churches standing against euthanasia. The theological stance of the majority is based upon the conviction that life is sacred because it is created and given by God, not man. Man's role is to protect and enhance life, but he may not take it, whether the patient requests to be killed or not, or whether those speaking for the patient request it or not.

This test to be applied now to newborn treatment policies is supported in Jewish, Roman Catholic and Protestant ethics. As noted in Part One, the Hippocratic Corpus as well explicitly prohibited euthanasia, a radical stance in some respects, given contemporary Greek mores. But this test and criterion would not necessarily flow inherently from philosophical bioethics given its methodology and content. A mere calculation of benefits and harms according to "objective" reason and logic, without reference to the moral limitations imposed by a faith inspired belief in the "alien dignity" of human life, is at least open to the conclusion that in a given case killing a particular patient would be beneficial rather than harmful. A number of secular bioethicists do in fact so conclude.[178]

C. Careful and restrictive definition of quality of life considerations

In Part One of this thesis we demonstrated that all three branches of theological bioethics - Jewish, Roman Catholic and Protestant, in effect acknowledge that the sanctity of life principle does not prohibit the cessation or non-initiation of medical treatment under certain circumstances. But because there are some marked differences between what various theologians consider to be those circumstances, this test does not and cannot assume that there is only one infallibly legitimate Judeo-Christian view as to these quality of life criteria and circumstances. Nevertheless, if only to preclude applying to the selected policies an excessively general and all-inclusive test and criterion, a choice should be made and assumed as to the one or more quality of life stances which at least in this writer's view arguably best represent the Judeo-Christian perspective. In various forms and places in Part One such choices as to the legitimate scope and content of quality of life considerations were proposed, and should now be summarized here.

To a certain extent the differences between theologians in this matter are a matter of differences of emphasis or terminology than of substance. For example, as already suggested and to be confirmed below, in many respects expressions and criteria such as ordinary and extraordinary treatment, quality of life, medical indications, and so forth do not necessarily represent such distinctly different approaches as their various proponents sometimes claim. In many respects the terms are used more or less equivalently. For example, Paul Ramsey rejects the use of "quality-of-expected-life" criteria in favour of a "medical indications" policy. But on examining carefully what he means by the latter, it is arguable (as we shall do below) that the supposedly substantial difference may be more a matter of terminology or emphasis. In this third test of ours we have used the expression "quality of life" on the assumption that it can have rough equivalents in those various other expressions.

In Part One we demonstrated that the differences between the various theological positions on quality of life do not for the most part relate to the particular religious tradition or denomination of the bioethicists in question. Both Roman Catholic and Protestant bioethicists span a similar variety of viewpoints, and there is in some cases more affinity between theologians of different traditions than between co-religionists. As for Judaism, it would be incorrect to say that cessation of medical treatment is always prohibited, but it does stand at the most conservative end of the scale in allowing treatment to be withdrawn only when death is imminent and dying is in its final phase.

Beyond certain parameters the differences between Christian theologians on this matter of circumstances which justify non-treatment are not reducible to only differences in terminology or emphasis. As already indicated, the gap between, for example, Joseph Fletcher and Paul Ramsey on this matter is not only semantic but real and substantial. That being so we cannot simply affirm both as being equally legitimate representatives of the "theological" or Judeo-Christian perspective. Choices must be made, some approaches eliminated, and in the process of doing so the special contribution of theological bioethics in the matter of quality of life considerations arguably emerges.

As for the Hippocratic tradition, it does provide at least a general affirmation that the treatment of a patient may ethically be stopped. But the affirmation is very general, very conservative and is out of step with actual medical practice and attitudes. In the Hippocratic Corpus we read that medicine should, "refuse to treat those who are overmastered by their diseases".[179] And in the Code of Ethics of the Canadian Medical Association, an ethical physician "will allow death to occur with dignity and comfort when death of the body appears to be inevitable".[180] It is conservative in that strictly speaking that policy would call for treatment to be continued as long as physiological life can be preserved, a position arguably similar to that of Judaism referred to above and described in Part One. It is general in that the policy provides no additional criteria for determining at what point or with what sort of disabilities one will be considered "overmastered by diseases" or faced with "inevitable death".[181] And as we will indicate below, there is a significant disparity between that "official" policy and actual practice and attitudes. In both practice and opinion the criteria for non-treatment go well beyond imminent or terminal illness.

As for secular or philosophical bioethics, a distinctive feature as regards quality of life (compared to theological bioethics) is that the quality of life concept is very often proposed as a replacement for, rather than an expression of, the sanctity of life principle. As suggested in Part One, many philosophers (and a few theologians) assume that the sanctity of life principle is necessarily "vitalist" in meaning, imposing a duty to continue therapeutic or life-supporting treatment as long as a patient is biologically alive, no matter what the costs or prognosis. Having defined the sanctity of life ethic and principle in that restrictive manner, the quality of life approach is assumed to be a mutually exclusive alternative focused not on life itself as an absolute value, but on the condition or quality of a life. It is assumed in this view that the sanctity of life principle would not permit the cessation or non-initiation of a potentially life-saving treatment on quality-of-expected-life grounds. But as we suggested in Part One, that is a fundamental misunderstanding of the sanctity of life principle looked at in the light of its Judeo-Christian roots and more recent Christian ethics. There is no necessary incompatibility between sanctity of life and quality of life. There would be only if quality of life criteria are given too wide a scope. The legitimate scope and meaning of these criteria from the Judeo-Christian perspective are in our view those which follow.

Quality of life considerations from the perspective of theological bioethics should arguably include at least the following three elements, all of which should be looked for in the policies to be tested.

First of all treatment policies should not reject explicitly or implicitly the sanctity of life principle, or assume that quality of life considerations and the sanctity of life principle are necessarily mutually exclusive. Instead, policies should embody (or at least not exclude) the view that they can be perfectly compatible, and that understood in a certain way, weighing and acting upon the expected quality of life results of a contemplated treatment can show respect for the sanctity of a life rather than disrespect. On the other hand, the sanctity of life principle must itself be retained in order to clarify and test the ethical validity of quality of life judgments.

In that partnership the sanctity of life principle, like other general principles, serves as a principle of interpretation and test of moral rules and criteria.[182] It is essentially the commitment, conviction and stories invested in that principle which allow us to judge whether a particular quality of life consideration reflects and encourages respect or disrespect for the meaning and value of human life. On the other hand, precisely because the sanctity of life principle is abstract, it is too general to alone respond to the complexities and varieties of individual cases. It requires complementing by the sort of moral reasoning, rules and criteria involved in specific quality of life considerations.

Secondly, the "specific way" in which quality of life factors should be understood and used is by limiting their scope and influence on treatment decisions to matters beneficial to the individual patient in question. Benefit to the patient, not others, should be the overall limiting concern imposed in the light of the sanctity of life principle. The expression "quality of life" is, without further definition, too vague and elastic to be ethically useful.

For some it should include as decisive factors for or against treatment the consequent burdens, benefits and costs to others and to society. As indicated in Part

One, we do not agree that such quality of life criteria are compatible with the Judeo-Christian view of the meaning and holiness of individual human life. Burdens and costs to others (such as the family) are indeed relevant to how a patient is to be cared for after treatment, but they should not be the decisive considerations in deciding whether or not to allow a patient to die. While the issue of burdens on others is not totally separable from treatment decisions, and does merit consideration, those interests and rights of others should not be assumed to be of equal moral weight as the right (of the disabled newborn) to have his life sustained.

The benefit to patient rule interpreted and limited by the sanctity of life principle also excludes considerations such as "relative worth", "social utility", "social status". The sanctity of each individual life insists upon the intrinsic worth and equal value of every life, and excludes any tendency to "relativize" lives according to the subjective views and biases of decision-makers. Quality of life considerations can in our view be purged of such criteria and focus upon benefit to the patient on the basis of objective criteria and needs. To ensure that subjective and relativizing factors do not creep into treatment decisions will require much vigilance and self-examination by decision-makers and policy makers. There will always remain the temptation to clothe decisions for non-treatment which serve purposes other than the patient's, in garments of altruism.

A third element arguably central to the perspective of theological bioethics regarding the quality of life concept, is that non-treatment could be ethical in more circumstances than only that of the patient who is already dying. In view of what was noted in Part One about Jewish bioethics, this position will involve a disagreement with (traditional) Jewish bioethics on that point. Whether it will involve as well a parting of the ways with some neonatal treatment policies by Christian bioethicists remains to be seen below.

A patient who is irreversibly dying and for whom further medical treatment has become useless need not be treated. To do so would be only to prolong the dying process. To stop or not initiate treatment in such a case is simply to acknowledge the inevitable. But a number of circumstances could justify the non-treatment of the non-dying as well, without necessarily compromising the respect and protection owed to our fellow humans. One is the circumstance of serious brain damage. This would apply to a case in which a reliable prognosis indicates that brain damage is so extensive and irreversible that the newborn is not expected to experience even a minimal self-consciousness and free will. A second circumstance could be that of a patient for whom treatment would cause or perpetuate unreasonable burdens such as pain and suffering. In both circumstances patients can continue to live for long periods. But in such exceptional cases it is in our view impossible to see how they could have further interests or benefits in continuing to live. Respect for the sanctity of life itself would seem to argue that if for example a life-threatening but correctable complication should arise, the more ethical course would be not to treat it and allow nature to take its course. To so conclude is not to question the fundamental worth of the patient, or the fundamental and prima facie obligation to sustain life and avoid killing or abandonment. To restrict or terminate treatment in such circumstances implies no change in the way we value that person's life - only an acknowledgement of the limits and sometimes excessively burdensome nature of medicine.

D. The continuing duty to provide care and comfort

Though there are sometimes grounds for stopping or not initiating treatment for the dying and the non-dying patient, theological bioethics should insist upon the continuing obligation to make that patient as comfortable as possible for the remaining time. To stop attempting to save or cure does not mean one may also stop caring. To allow to die is not to wash one's hands of the patient, to go from doing something to doing nothing. The same fidelity and respect is owed to that patient's life after a decision for non-treatment as before. The difference is mainly in the medical purposes (now care alone not cure), and usually in the medical means as well. It should be noted however that sometimes only caring for those being legitimately allowed to die will involve fairly extensive treatment, including surgery. But it will be to maintain an important function or provide comfort for the time remaining, not to save or prolong life. The obligation of continuing care flowing from the sanctity of life principle and the faithfulness and love owed to patients does not therefore exclude on occasion extensive and radical treatment. From the Judeo-Christian perspective the words "with care" should always be added to the expression and reality of "allowing to die".

E. Treating and protecting the mentally and physically disabled equally

A practical test of the seriousness with which a treatment policy takes the sanctity of life principle, will be its stance toward the mentally handicapped. That principle urges us to assist and protect those in greatest need, those who are the most helpless, and in many respects that is the case with the mentally handicapped, whether newborns or not. But as already noted in Part One, it is precisely because the mentally disabled often require more care, services and financial outlay than do other handicapped patients, that some are inclined to see needed treatment of them as a waste and a threat to the quality of life of those not so burdened.

But from the Judeo-Christian perspective, the mentally handicapped should not be treated differently from those who are physically disabled. In exceptional cases life-saving or life-prolonging treatment for both will not be indicated either because they are irreversibly dying or because further treatment would be more harmful than helpful to them. But apart from such cases both th[illegible] physically and the mentally handicapped deserve to be treated equally and with all the care and services possible. From the Judeo-Christian perspective what is "possible" should not be defined by what is convenient without excessively burdening others or society or according to the bounds of reason alone. If societal institutions and structures would be overburdened by providing the care needed for mentally handicapped newborns to survive and flourish to the limits of their capacities, the serious Christian or Jew would respond that we should urge the shifting of societal priorities and finances. For that reason there is a degree of radicalism in this attitude and test, a radicalism willing to challenge the structural status quo to a degree not generally found in secular bioethics.

While it may not be possible to apply this test to all the treatment policies to be considered since not all of them refer explicitly to the mentally disabled newborns, it may be possible to draw some conclusions about how it would likely be applied to such patients by the general thrust of the policy and explicit criteria on related issues.

F. Limits to parental decision-making authority

In view of the theological perspective we have chosen and described to this point, all decision-makers are bound by the same moral imperatives and limits. Respect for the sanctity of life, a restrictive definition and application of quality of life criteria, the exclusion of euthanasia, the continuing duty to provide care and comfort, and the equal treatment and protection of the mentally disabled newborn, all these duties apply to parents as well as physicians. Parents after all have a moral duty (and a legal duty as well as we shall discuss in Chapter IX) to provide needed care and protection of their children. They are not therefore morally (or legally) free to refuse treatment for their child in all circumstances and for any reason they regard as sufficient. Respect for the sanctity of the life of their newborn child above all else obliges them to provide, or seek or consent to life-saving or life-sustaining treatment when it is therapeutically useful.

Because parents and treating physicians have essentially the same moral duties in this regard, duties attached essentially to their own roles and responsibilities, parents cannot morally relieve physicians of their ethical obligation to treat by withholding their own consent. Parents do indeed have decision-making authority over the care and treatment of their children, but it is not an absolute authority. It does not extend to making decisions with potentially harmful consequences to their child, especially those of abuse or death. This ethical position on the limits and duties of parental authority can be found in the social and medical ethics of Judaism, Roman Catholicism and Protestantism. It is also of course affirmed by many secular ethicists as well.

Should parents refuse what a physician believes is useful and needed life-saving or life-sustaining treatment, there are in our view no good ethical reasons why he must acquiesce. Should they continue to refuse consent, his duty would be to seek court authorization to proceed. To allow parental consent to be decisive in such cases runs the risk of giving priority to parental wishes at the expense of their childrens' lives. Parental refusal over the objections of the physician need not of course always mean that they are wrong as to what would be to the benefit of their child. It could also be the physicians who are in error by erroneously or too hastily opting for a treatment which may in fact be therapeutically useless and unjustified in view of the newborn's condition. If the disagreement persists it may well be that the court appealed to will decide on good moral and legal grounds that the parental refusal was justified in the circumstances.

G. Attitudes of openness and caution

These two attitudes, openness and caution, may seem contradictory but they need not be. Each underlines a highly desirable attitude in policy-makers, and quality in their policies, and the goal should be a balance between them. Each alone would be inadequate. Each follows from an important conviction in Judeo-Christian bioethics. One is that of man as "co-creator" or "co-actor" with God, one expression of that responsibility being the way treatment policies are shaped and decisions made. The new conditions and challenges offered by continually evolving modern medicine and medical technology are viewed by the serious Jew and Christian as new God-given possibilities calling for new and creative responses. As with everything in creation, modern medicine can be used, shaped and controlled, or it can dominate and overpower.

From the theological perspective an attitude of openness in the context of neonatal medicine would arguably involve among other things a rejection of the view that it is enough in the face of new medical and moral complexities to simply repeat old formulas from simpler times, or to merely wave the sanctity of life or natural law banners without further qualification. An open attitude would be ready to admit that old recipes without some new ingredients and more sophistication will not meet the new challenges and possibilities. Policies which are simplistic and general (for fear of "playing God"), or which do not reflect sufficient awareness of the medical data and a careful weighing of relevant principles and values, invite the bureaucrats and technocrats to make the policies and decisions on strictly bureaucratic and technocratic grounds.

But theological bioethics based upon Judeo-Christian faith invites equal attention to the sinfulness and finitude of man, and the consequent need for caution and self criticism to balance our creativity and willingness to be co-actors in God's creation. Given our sinfulness and our finitude, the policy-maker and decision-maker will be tempted by delusions of infallibility, a characteristic which may well be traceable in the resulting criteria or guidelines proposed. Our fallibility, ignorance and "tunnel-vision" will always tempt us, sometimes unwittingly, to substitute our own interests or those of society for that of the newborn child, sometimes masquerading that goal in altruistic terms. That tendency as well is sometimes traceable in the policies resulting. All of which argues for the need for policies with built-in mechanisms and incentives for self-criticism and restraint, lest those with responsibilities in life and death matters usurp God's dominion over creation and life.

H. Fairness, toleration and interdisciplinarity

To this point we have summarized what are proposed as the major elements of a theological stance on the subject of treatment, transformed into the form of tests to determine the contribution of theological bioethics to newborn treatment policies. It was also suggested that in many respects similar elements and tests could be extracted from many expositions in the sphere of secular bioethics, at least as regards content. But in some other respects there are important differences as well, especially regarding the scope, intensity, motivation and expression of moral imperatives based upon adherence to the Judeo-Christian tradition and to various religious and moral communities within that tradition.

But in a pluralist society such as ours in which medicine, health care institutions and neonatal units must serve patients and families of various religious and cultural traditions and in some cases none at all, it would be unrealistic to expect to find what we have proposed as the distinctive features of theological bioethics explicitly reflected and enforced in treatment policies. But what we could expect to find in our pluralist society are treatment criteria and guidelines which will at least be able to accommodate and respect those viewpoints and convictions, and not to exclude them explicitly or implicitly. The same would of course apply to the views and convictions of other religious and cultural communities, assuming of course that these positions do not restrict the legitimate freedom of others and are within the bounds of law. That treatment policies should manifest this accommodation, respect and tolerance in a pluralist society is quite consistent with what we indicated in Part One as the unique and important contribution of secular bioethics - a commitment to fairness, toleration and the fashioning of procedures to ensure consent, autonomy and self-determination.

Fairness is a crucially important test of treatment policies, especially in a pluralist context. Given the variety of preferences, cultures, backgrounds and ethical views in the families and staff using and servicing our hospitals and neonatal units, it becomes all the more important to ensure that all the parties involved are treated justly and equitably. This is especially so for the sake of the one party unable to express a wish, namely the disabled newborn baby. A policy is fair to those babies if it seeks to provide equal protection for the rights and interests of all the disabled newborns to which it applies. A hospital or unit is being fair if the <u>same</u> treatment standards and criteria are applied to <u>all</u> the newborns in the care of that hospital or unit. To guard against arbitrariness and inequities, fair policies should also provide for the review and appeal of treatment decisions (e.g. to other physicians, ethics committees or courts), when an interested party (e.g. parents, physician, nurse or institution) feels the decision may be prejudicial to the health or life of the baby.

One way of helping to ensure tolerance and fairness in treatment policies is to allow all the relevant disciplines and perspectives to contribute to their formulation. The three most obvious and important ones are medicine, bioethics and law, but others have much to contribute as well, for example those of sociology, economics and psychology. Medicine, bioethics and law each have indispensable roles to play in making these policies, a policy made by any one of them alone risks being incomplete. Medicine provides needed medical/scientific data, diagnostic and prognostic experience, and medical wisdom. Bioethics provides special skills and attention to the sorting out, ranking and balancing of the relevant values, rights and principles. The right input from the legal dimension does not necessarily imply legislation, legal mechanisms or law reforms. But it should ensure that the treatment policy provides for the allocating of rights and duties and the resolving of conflicts, that the policy stays within socially acceptable boundaries, and that it will be public and subject to public scrutiny and review.

Merely because a newborn treatment policy is to apply in a hospital or neonatal unit does not mean it should be formulated by physicians alone, without contributions and review by the public and other disciplines. Choosing the mix and ranking of values necessarily involved in these life and death matters transcends both the mandate given by society to physicians, and the training of the physician qua physician. There is a large quotient of <u>public</u> policy involved in these policies, and the rights and values which are to apply and prevail should not therefore be determined by any single discipline alone, not even the one closest to the scene. But if interdisciplinarity is to be effective, every effort must be made to get beyond the mutual suspicions and antagonisms which tend to limit collaborative efforts in the medical arena.

I. The participatory contribution of theological bioethics

This last test will of course be applicable mainly to bioethical policies, the subject of Chapter VIII. As suggested above,[183] there are arguably three predominant stances which the theologian could adopt in policy-making, and the choice of stance could be expected to leave traces in the policy itself or in its supporting argumentation. The three roles suggested are those of preserver, prophet or participant. The theological bioethicist as "preserver" would essentially seek to formulate policies which reflect and protect the moral viewpoints of a particular religious community, expressed in traditional and explicitly theological terms, often without the specificity or sophistication needed in less homogeneous contexts. Policies formulated from that perspective may be suitable for religious institutions but not for those designed to operate in a pluralist context. The theologian as "prophet" contributing to a policy for a pluralist setting would tend to denounce the moral views of others and seek to have his own theological perspective incorporated into a policy more or less to the exclusion of other viewpoints. The traces of both these positions in policies and supporting arguments would be overtly religious language and concepts and/or positions and criteria explicitly or implicitly founded on a particular religious perspective not shared by others.

The preferred role suggested above for theology and theologians in formulating treatment criteria for our pluralist society is that referred to as "participation". In this model, the theologian has definite points of view and convictions and he defends them with vigour, but nevertheless sees his role as a partner contributing to a common undertaking along with others (e.g. philosophers, physicians, administrators and perhaps theologians of other religious communities). He is prepared to respect and learn from their moral insights. He is also prepared to help design treatment criteria which reflect and leave moral space for the legitimate views and choices of patients and staff belonging to a variety of religions and cultural communities. If he is successful, the resulting criteria:

- will respect the various elements of a theological perspective referred to in the previous tests;
- but will not normally be formulated in explicitly theological language and argumentation,
- will promote consensus by being criteria acceptable from both humanistic and theological perspectives to the extent possible;

- will allow sufficient latitude to accommodate legitimate differences of emphasis in view of the variety of religions and cultural traditions and personal choices inevitable in view of our pluralist society;
- will not be so general that they provide little real guidance, but address with as much specificity and sophistication as possible both the moral dilemmas and medical complexities involved in the treatment of newborns.

In view of the above, this test of newborn treatment policies proposed by theological bioethicists will assume that the theologian as participant should, like the philosopher and secular bioethics generally, place a high priority on tolerance and freedom. Given his particular convictions about for instance the sacredness of life, the scope allowed to the variety of tolerable views will often be narrower than that acceptable to the secular bioethicist. For example, a theological bioethics which rejects euthanasia and subscribes to the restricted definition of quality of life proposed above, cannot co-exist in the same policy with a view which permits euthanasia and opts for a "social worth" definition of quality of life. Unless of course the policy in question was at such a level of generality and abstraction as to be relatively useless for moral guidance.

But assuming that the differences are not as incompatible as that, tolerance and freedom in allowing some differences and varieties should be high priorities in theological bioethics and not just in secular bioethics. Justification for these attitudes within the theological perspective can be based not just on the pragmatic realization that our pluralist society exists and is here to stay, but also on principles to be found within theology itself such as freedom of conscience and religious tolerance. That the difference between theological and secular stances evokes tension is undeniable. But that tension (within certain proportions) can also promote a healthy dialectic in which each learns from the other, a learning and influence which goes in both directions. To find a degree of that tension, dialectic and mutual influence in policy-making and in the treatment policies to be tested need not therefore be taken as a sign of failure by one perspective or the other, but that each is making the contribution it ought to be making in our pluralist society.

2. Newborn disabilities - the medical data, the capabilities and limits of neonatal medicine

Having outlined the ethical tests which will apply in the chapters to follow, a preliminary task which remains is that of indicating, at least in summary form, the medical facts and conditions which comprise serious newborn handicaps. It is these categories of disability, combined with the ever-expanding capabilities of neonatal medicine, which together make necessary increasingly sensitive and sophisticated ethical responses.

The disabled newborn infants of interest to us generally fall into two main categories - those born with congenital abnormalities,[184] and those born with low birth weight. A brief summary of the medical data and implications of each category is in order, beginning with that of congenital abnormalities.

A. Congenital abnormalities

Unaided nature itself provides that most seriously defected fetuses are discarded before birth. It has been known for some time that the second largest reproductive mortality occurs during early pregnancy, after implantation (the largest loss occurring during the seven day journey of the fertilized egg - the zygote - from the uterine tube to the uterus).[185] It has been estimated that about twelve percent of the implanted embryos and early fetuses spontaneously abort.[186] About three percent are stillborn.[187] Examination of the fetuses spontaneously aborted indicates that their incidence of chromosomal defects is twenty times higher than in live-born infants, and neural tube defects (e.g. spina bifida) occur six to eight times more frequently in spontaneously aborted fetuses than in the live-born.[188]

Whether born prematurely or not, it has been estimated that in the United States about four percent of the children born each year have a detectable congenital abnormality. They are the result of defective genes, environmental factors or chromosomal abnormalities. The causes of many birth defects are either unknown or the result of a complex of factors, both environmental and genetic.

Within the category of congenital abnormalities, two types of defect or handicap have been the object of most ethical and legal attention. One is that of neural tube defects. In the United States and Canada it is estimated that approximately two of every one thousand newborns are affected by these defects, making it the most common of the serious newborn congenital abnormalities.[189]

Two types of neural tube defect are particularly relevant to our concerns. One is that of anencephaly, in which most or all of the brain is absent. This condition generally makes impossible the development of consciousness. Those newborns so affected generally die within a few days of birth at the most. A second type of neural tube defect is that of spina bifida (meningomyelocele). It results from defective formation of the neural tube, one of the first organs to develop, and which eventually forms the spinal cord and brain. Spina bifida ranges widely in severity, and can affect other organ systems as well. Those affected range from very severely physically and mentally disabled to those with normal intelligence and manageable disabilities. Many newborns with spina bifida respond well to surgical and rehabilitative therapy. Among the problems which these newborns, their families and physicians must face are especially one or more of the following: paralysis or weakness below the level of the defect, loss of skin sensation below the lesion, incontinence of bowel and bladder, hydrocephalus (in sixty-five to seventy-five percent of the patients.)[190]

But there is a second type of defect within the congenital abnormality category which has probably received the most attention in ethical and legal analyses in Canada and the United States. It is that of newborns who have a permanent and irremediable defect, but one which itself is not life-threatening, combined with an additional, life-threatening but correctable problem. The clearest instance of this combination is that of Down Syndrome (mongolism), which is irremediable but not life-threatening, combined with gastrointestinal blockage and/or congenital heart defects, both of which are life-threatening but correctable. Infants born with Down Syndrome are mentally retarded, but the retardation ranges from mild to serious and the severity can seldom be diagnosed accurately early in the infancy. It is estimated that the frequency of Down Syndrome is approximately one in every seven hundred live births.[191]

Their lives are not threatened by the Down Syndrome itself, but (in a minority of cases) can be threatened by the associated congenital defect. Correcting that complication would in most infant patients not afflicted with Down Syndrome be considered more or less "routine" and clearly indicated. There is of course a degree of risk involved in these surgical corrections, but operations to correct gastrointestinal blockage for example are generally successful. If not surgically corrected, sometimes in the first weeks of life, it could prove fatal. Those born with a gastrointestinal blockage for example would develop a fatal pneumonia or starve to death if not treated, since they cannot be fed.

B. Low birth weight infants

The second major category of birth defects, is that of infants born with low birth weight. While the tendency in legal and ethical analysis is to focus on Down Syndrome and spina bifida babies, in actual practice they represent only the "peaks" of the birth defect problem. Prematurity and resulting low birth weight affect many more newborns and raise more difficult ethical and legal treatment dilemmas than do either of those two congenital abnormalities. Approximately seven percent of those infants born each year can be classified as low birth weight infants (that is, those weighing not more than 2500 grams), in the United States comprising a total of about 230,000.[192] The mortality rate of low birth weight infants is extremely high compared to all the other populations treated in hospitals. As a general rule, the lower the birth weight the more likely such infants are to die. One source based on a study of a number of medical centres between 1974 and 1976 reported that these infants were forty times more likely than normal birth weight infants to die during the neonatal period and five times more likely to die between a month and a year after birth.[193]

The low birth weight infant typically has immature lung development and as a consequence suffers from hyaline membrane disease. Those with any hope of survival must therefore be placed on mechanical ventilators to provide them with sufficient oxygen. But this treatment itself can in some cases cause death and increased distress - pulmonary hemorrhage, brain damage and blindness are the most serious possibilities. Since their gastrointestinal tracts are too undeveloped to absorb food, they must be fed intravenously, in itself a difficult and risky undertaking given the infant's small size and immature heart and kidneys.

Hospitals have made great strides in recent years in both Canada and the United States in responding to the challenge and tragedy of congenital abnormalities, low birth weight infants and other forms and combinations of birth defects. Today in both countries neonatal intensive care units exist from coast to coast and are provided with highly sophisticated technology and highly trained staffs of physicians and nurses.[194] Treatment in these units is very expensive, given the technology involved as well as the number of highly specialized staff.[195] These neonatal units have contributed to greatly reducing the mortality rates of infants born with defects and with low birth rates.[196] There is no doubt that especially since the 1960's very many newborns have been saved who previously would have died, and very many of them not only survive but do so with full recoveries or only mild handicaps and go on to live full and productive lives.

But there is another side to the coin. The very success of modern neonatal and postnatal care has presented law, ethics and society with new problems, challenges and possibly (according to some) failures. Some of these newborns who can now be sustained by the use of new technology and skills for at least a brief period nevertheless continue to have their ultimately life-threatening disabilities, but new medical technology can at least extend the dying process by a few weeks or months. But should it always be done? Others have handicaps or complications which are not necessarily life-threatening but they are very seriously disabled and/or in varying degrees of irremediable pain. Continuing to provide only normal basic care including feeding and infection fighting makes it possible for some of these newborns to live on for many years. But should it always be provided? Still another class of newborn are those born retarded and who are discovered to have a life-threatening complication which can be readily corrected thanks to new techniques and technology. But should it always be corrected in view of the quality of expected life of some of these children?

Chapter VII: Medical policies as practiced and formalized

1. Physicians' views, preferences and practices - from surveys and studies

In this first of two parts in this chapter, attention will focus on the views of physicians, mainly pediatricians. Consideration of more detailed and specific treatment criteria in the form of "full-blown" policies will be the subject of the second part of this chapter. Here in this first section, the views will be gathered from surveys, interviews, articles and hospital records. Our first justification for including these sources and the attitudes thus provided under the heading of "policies", is that these preferences and value choices of practicing physicians constitute in effect "personal" policies. While these trends and preferences cannot in all respects be assumed to represent actual practices, they can at least be assumed to influence practice, whatever is dictated by "official" policies in the form of ethical guidelines and codes.
A second justification is that the more formal and detailed treatment policies and criteria applicable to an entire branch of medicine (such as neonatology) must (among other things) confront either approvingly or disapprovingly precisely those actual trends and preferences of the practitioners. If not, those more formalized policies will be dismissed by both physicians and bioethicists for having missed the (medical and moral) points.

While many of the trends and viewpoints which follow do not directly reveal their underlying moral stances and assumptions, it will be our task to deduce these when possible and to evaluate them in the light of the tests proposed above.

A. Sanctity of life and quality of life - the influence of burden to others and mental disability

In this section, a number of related questions are of particular interest, all of them arising from the tests proposed above regarding the sanctity of life, quality of life and the equal treatment of the physically and mentally disabled newborn. Rather than treat each of those tests separately as was done in describing their elements above, in what follows they are to some degree "telescoped". We do so because of the essential interrelationship of sanctity of life, quality of life and mental disability, and because the relevant sources such as surveys assume that relationship in their questions.

Of major interest to us in the attitudes and preferences of physicians are these questions: is the sanctity of life (or equivalent) of a newborn generally understood in a "vitalistic" manner, and are sanctity of life and quality of life seen as mutually exclusive? How wide a latitude is generally granted to quality of life considerations, what qualities in particular are valued, how are they balanced, how are these qualities justified as normative criteria, and what influence on treatment decisions does the "social context" have? In particular, what normative weight is given by pediatricians to mental retardation as compared to physical disabilities? Does religious affiliation and religiosity make any apparent difference to the views held on the above points?

Since our main goal will be to determine the prevailing normative values and ethical systems influencing the preferred quality of life criteria, it might be helpful to provide a summary of the normative options. If we gather together various elements already discussed at earlier points in this paper, we could arguably conclude that there are essentially three choices in normative systems relevant to these sanctity of life and quality of life issues.

The first is a deontological or rule-based system. Its moral foundation is that individuals have an inherent sanctity or dignity and inalienable moral rights. What one may and may not do to individuals is determined and limited by that inherent sanctity and those inalienable rights, and not by the beneficial or non-beneficial consequences of living for a longer or shorter period. Those subscribing to this moral stance and system would conclude that given the inherent worth of a newborn one may not directly or indirectly kill an infant, and one must support all human life including the weakest and most vulnerable of its members. In its absolute form, the deontological stance would be equivalent to "vitalism".

The second such moral system is that of consequentialism or utilitarianism, according to which the value of life is measured against the consequences for that individual's quality of life (personalistic consequentialism) or the quality of life of others (social consequentialism).

But a third moral system is essentially the deontological one but without being absolutist. It allows for some qualifications and exceptions. It permits taking into consideration the patient's medical and social circumstances and, by exception, concluding that the duty to preserve life in a particular case is superseded by one or more of these other considerations and values - life support in such a case has become "extraordinary" or "unreasonable". But this approach allows only a very limited scope to the newborn's external or social context and is therefore generally dubious about the moral weight of social quality of life criteria such as the impact (of treatment) on the disabled child's family, or the financial burden (of treatment) on the family or society. As indicated above, in this writer's view this third ethical system is the one most consistent with the central convictions and contributions of the Judeo-Christian tradition applied to this issue.

We will conclude in effect that the trends in the quality of life views of physicians indicate that the implicit normative approach with the most influence on them falls somewhere between the second and third of the three listed. If the trends indicated by existing surveys and personal testimonies are to be believed, the commitment of pediatricians to supporting the lives of the weakest and most vulnerable members of society is greatly qualified by considerations more in the nature of social considerations external to the disabled newborn and his medical condition. In some cases these external conditions are weighed in terms of benefit to the child, e.g. the availability of needed support and rehabilitative services. But in other cases a predominant social consideration sufficient to disqualify a newborn from treatment will be the burden on others, e.g. the impact on the family if that child should survive. The predominant trends in these views imply that consequentialism is more influential than the deontological stance, a consequentialism which in many instances gives the benefits and burden to others as much or more moral weight as the rights and benefits of the individual disabled newborn. If that is an accurate assessment, then the role and influence of that branch of theological bioethics which we advocate, is not presently of much influence in the consciences and practices of many pediatricians.

i) The physician as "moral entrepreneur"

A first finding of relevance from existing surveys and other sources is that the great majority of pediatricians do not have an absolutist or vitalistic view of their duty to save the lives of newborns. For example, a 1977 national survey in the United States reported that 83 percent of responding surgical pediatricians and 81 percent of pediatricians other than surgeons responded "no" to the following question: "Do you believe that the life of each and every newborn infant should be saved if it is within your ability to do so?"[197] It is interesting to note that as regards religious affiliation, within the surgical group of pediatricians Catholics emerged as the most "conservative" (61% answered "no" and 39% answered "yes"), and Jews as the most "liberal" (97% answered "no" and 3% answered "yes"). Within the pediatric group it was Jews who emerged as the most "conservative" (64% answered "no", but 36% answered "yes").[198]

In principle this majority view maintaining that not every newborn infant need be saved even if it is possible, is of course compatible with the non-vitalistic bioethical view we formulated as our test. A more important and difficult test is of course that of the medical conditions and other criteria which could justify non-treatment.

A second finding of relevance, one bringing us closer to views about those conditions and criteria is that when asked which of several factors and conditions most coincides with their own concept of "heroic" or "extraordinary" care, most pediatricians appear to grant that that concept should not be defined by the nature of the treatment but by the situation in which a treatment is used.[199] This view as well would in principle be quite compatible with our tests, and with the general position of both theological and philosophical bioethics.

A fundamental element of the sanctity of life/quality of life standard we are applying is that the bias should always be that of saving life, and that not to do so for those not already dying should be seen as exceptional, requiring much caution and the application of specific medical criteria. That stance was proposed as the one most compatible with the Judeo-Christian tradition and the most respectful of the personhood, dignity and rights of the newborn. But in some medical opinions one detects a bias in the other direction, one implying that those not ready to let a disabled newborn child die are likely to be victims of merely instinctual forces, and/or motivated by selfishness and legalism, while those prepared to allow the child to die are more likely to be acting from religious convictions and with more sensitivity. The very influential positions and writings of Doctors Duff and Campbell typify this approach. Duff for example has written:

> The initial reaction of most parents at birth is, "Don't let our baby die. Make him live". Firm rooting of a parental death wish for a defective child takes days, at least.... In human and other species, there is a powerful altruism which defends and nurtures the young.... Some parents who are aware of very poor prognosis report deep religious convictions that they should allow their child to die. But, sensing staff bias and feeling vulnerable to attack by cynics, they keep that to themselves.[200]

Duff and Campbell tend to portray as villains with misplaced priorities and principles most of the actors involved, except parents and a minority of physicians. About courts and committees Duff writes:

> There is a great potential for conflict of interest in hospital committees, regulating agencies and courts because these parties have some agendas far removed from the child's and family's interests.... Courts must be more concerned about legal doctrine than about particular child or family problems and needs.[201]

As for physicians and administrators who oppose choosing death for disabled newborns, they (but not also those who do choose death) are referred to pejoratively as "cynical", "moral entrepreneurs", "crusaders against death and disease", or "paternalistic". For example, Duff writes that:

> ... nursery policy is shaped by two main forces, neither rooted consistently in the values of families. The first is medical opinion which in a minority of instances represents a rigid "moral entrepreneurship". Whether or not such rigid moral policy exists in the nursery, institutional leaders (administrative, medical and nursing) as a second and much stronger force commonly compel it upon the nursery. These leaders emphasize the appealing ethics of the crusade against death and disease and point out their obligation to observe homicide laws.[202]

Implicit in these attempts to reverse the present bias in favour of saving life, and in the hostility to allowing the sanctity of life principle a large role in decision-making, is the assumption (already rejected by us above) that sanctity of life and quality of life are mutually exclusive and opposed. As well, Duff and Campbell for example, tend to equate sanctity of life concerns with a "disease-oriented philosophy", and exclusively "technical" considerations, whereas quality of life concerns are equated with a "person-oriented philosophy", stressing the needs and values of the child and family. They write for example that:

> ... we believe that much controversy results from conflicts between two distinct but closely related philosophies of care, one mainly oriented to the disease and the other focused primarily on the needs of the individual patient (the person). The first philosophy implies that life itself is all that matters; that death represents the ultimate in human and medical failure, something to be avoided at all costs. The second philosophy considers that the quality of life should be the primary concern.203

Assuming as they seem to that the two philosophies will be in conflict, and preferring the second approach for both extreme and "borderline" cases, they are prepared to jettison both the normative role of traditional principles such as the sanctity of life, reject what they see to be the intrusive and merely technically-oriented restrictions of courts and committees, and grant moral autonomy to the family and its physician. Referring to families and physicians, they maintain that:

> ... they must be entrusted with more freedom to change or to ignore commonly accepted principles if the values of patients and families in the many unique situations of living, illness and dying are to be protected.204

Extending that position still further, to law and religion generally, Duff writes:

> The primary aim of medicine is personal and social, not biologic; nor is it religious or legal. And the profession of medicine in addition to recognizing its own limits often must keep some socially useful or necessary legal and religious doctrines a little distance away.205

Whereas Duff is quick to brand the treatment of seriously disabled newborns as paternalism (and no doubt that label is sometimes accurate), one detects an inescapable element of paternalism in the preferred bias of allowing them to die. By arguing that medicine should make its decisions in these matters independently of law, moral principles or social restraints, physicians alone would become the arbiters of the rightness of parental wishes. Being subject for instance to courts or committees:

> ... would give away or destroy a central ethos of the profession along with that of the family. I refer to the profession's responsibility, in working with individual patients and their families, to establish a standard of conduct for itself and to assert the freedom to do what it considers best.206 [Emphasis added]

ii) Mental retardation as a counter-indication of treatment

Nor do viewpoints of some physicians demonstrate a strong commitment to some of the other elements of the sanctity of life principle proposed above. Among these elements would be an unwillingness to sacrifice the rights and needs of individual patients for society as a whole, and a commitment to the equal rights of the weaker members of society, in this case the seriously disabled newborn especially the retarded. The positions of Duff and Campbell for example do not demonstrate much influence of those particular planks in the bioethical platform we proposed as normative. Appealing in large part to eugenic considerations, they maintain that:

> ... since many congenital malformations have a genetic component, if great efforts are made for survival in all instances, it is possible that future generations might be harmed. In this case, as in others, the rights of society as a whole, including future society, appear to conflict with the rights of individuals. Thus, over and over again we have to face the difficult question, to what extent if any, must the strong and healthy respect the rights of the weak and unhealthy to survive and reproduce?[207]

The viewpoints and apparent practice of many pediatricians and neonatologists demonstrates a definite bias against treating disabled newborns who are retarded with the same criteria and zeal as those not so afflicted. Duff and Campbell for example make it clear that correcting a life-threatening but correctable problem such as atresia in a Down's syndrome child is very likely "medicine at its worst", because the defects such as mental retardation remain.[208] Not of course that that position is shared by all physicians. A pediatrician who disagrees with Duff and Campbell on that (and other) points is Norman Fost. He by no means opts for a "vitalist" approach, but argues for the rights of the retarded newborn as follows:

> I assume Duff would willingly resort to legal authority to interfere with flagrant physical abuse, or refusal to repair a duodenal obstruction in any otherwise normal child.... It appears that it is only when the child is retarded and physically handicapped that Duff thinks it morally preferable to assign him a category less equal than other persons, inaccessible to state intrusion. This policy

> apparently rests on the assumption that retardation constitutes a sufficient reason for giving validity to parental actions which would be clearly objectionable if applied to a normal child. While such a policy might be defended for those children so impaired that it is difficult to agree that they have any interests (such as an anencephalic), its rationale is less clear when applied to children who have an excellent chance for a happy, fulfilling life (such as Down's syndrome). ... As I understand Dr. Duff, the principle of "equal justice under the law" should be modified, "... except for the retarded".[209]

Though Duff and Campbell by no means represent the only or even necessarily the majority view on this issue of retardation, several pediatrician surveys suggest that a not inconsiderable number agree. The surveys indicate that the newborn patient from whom treatment is least likely to be withdrawn is the salvageable child who has only physical damage. A brain-damaged child, even one who is moderately brain-damaged as are many with Down's syndrome (i.e. mongolism), is less likely to have a correctable life-threatening complication corrected than is a newborn with the same complication who is not brain-damaged.

Crane's 1975 national survey in the United States provides much useful information in this regard. She concludes for example about salvageable newborns that:

> The pediatric heart surgeons ... were much less likely to say that they would perform cardiac surgery upon children with an

> accompanying brain anomaly, mongolism, than upon children with an accompanying, severe, but treatable physical anomaly. The brain damaged children clearly have a lower potential for performing social roles than the physically damaged children. The interview suggested that the medical standards which are applied to mentally retarded children are different from those which are applied to normal children. A pediatric cardiologist said: "Heart problems are usually fixed in normal children, but they are not usually fixed in the mentally retarded. For the mentally retarded they are only fixed if the patient is in gross discomfort. Such discomfort is rare."210

Crane reports that in answer to a question about withdrawal of treatment, 66 percent of pediatricians responded that they would not do "heroic" treatment or surgery (e.g. a shunt for hydrocephalus, or a blood transfusion) for salvageable mongoloid newborns, whereas only 18 percent said they would not do so for newborns with severe physical damage.[211] Even when the questionnaire results indicated that a pediatric service in a particular hospital was in favour of treating mentally retarded children, a study of the hospital records in the same hospital indicated that the proportion actually treated and resuscitated was considerably lower than the questionnaire responses suggested.[212] Crane interprets this discrepancy as follows, "... there may be a conflict between the official medical ethic in this area and the pressures which physicians face in actual practice. In describing their attitudes some physicians pay lip service to the traditional ethic which in practice they find to be inappropriate."[213]

Somewhat similar views on the subject of treating newborns with mental handicaps are provided by other surveys of pediatricians. For example, the nationwide survey of pediatric surgeons and pediatricians by Shaw, et al. included the question:

> Would you acquiesce in parents' decisions to refuse consent for surgery in a newborn with intestinal atresia if the infant also had (a) Down's Syndrome alone, (b) Down's syndrome plus congenital heart disease, (c) anencephaly, (d) cloacal exstrophy, (e) meningomyelocele [spina bifida], (f) multiple limb or craniofacial malformation, (g) 13-15 trisomy, or (h) no other anomalies, i.e., normal aside from atresia?214

Whereas the pediatric surgeons by their responses understandably ranked as the most severe and hopeless conditions those of anencephaly and 13-15 trisomy, babies with Down's syndrome plus a heart condition were ranked as having the third most severe condition, even though the atresia and heart condition are correctable and usually would be corrected in babies not retarded. The percentage of those who would acquiesce in parental refusals to treat infants with anencephaly was 95.9%, 86.5% for infants with 13-15 trisomy, 85.0% for infants with Down's syndrome plus congenital heart disease, 76.8% for infants with Down's syndrome alone.

The survey of Massachusetts pediatricians by Todres, et al. in 1977 provides slightly different results to a question similar to that asked by Shaw (baby with duodenal atresia, Down's syndrome and parental refusal of surgery), but the majority still felt the atresia should not be treated and the baby should be allowed to die. In this case 51% opted for no surgery and 46% recommended surgery.[215] Of those preferring treatment, only 40.2% would pursue a court order to authorize it over parental refusal. The majority would not seek a court order and would try to convince the parents to accept the physician's point of view.

A survey of California pediatricians in 1975[216] reported that in answer to a similar question about a newborn with Down's syndrome and atresia, 61% would not perform the operation to correct the atresia, in effect allowing the baby to die. Only 17% said they would do "everything humanly possible". Even if the newborn had Down's syndrome and no complications, 22% favoured active or passive euthanasia.[217]

What do surveys and other sources establish about the influence of considerations other than the newborn's strictly medical condition, for example parental wishes, religious motivation and affiliation, effect of treatment on the family, the family's socio-economic status, the implications for society generally? Parental wishes prove to be a major influence, so much so that it will be treated separately below in its own section (p.223).

iii) The influence of religion and religiosity

Religious motivation and affiliation undoubtedly influence sanctity of life/quality of life decision-making involving disabled newborns, but it is difficult to determine the nature and extent of that influence conclusively on the basis of existing surveys and published viewpoints. As already indicated above, Duff for example reports that parents of disabled newborns often base their decision to allow their child to die on religious convictions, and he even implies that those who oppose treatment in these cases (whether parents or others) often do so not for religious motives but more likely from instinctive reflexes or professional self-interest.[218] Undoubtedly both claims are sometimes true, but Duff does not provide further details as to the religious affiliation or degree of religious commitment of those influenced by religious convictions, or the particular religiously inspired convictions or principles on which they base their preference for non-treatment.

Surveys of pediatricians generally support a conclusion that religion does influence pediatrician decision-making for or against treatment of disabled newborns, and that Catholic pediatricians may be more likely than their Protestant or Jewish colleagues to opt for treatment. But it is not certain whether religious affiliation alone or religiosity (i.e. degree of commitment to one's religion) is the greater influence and the more important predictor of physician decision-making.

Shaw, et al. addressed the question, "Do you believe that the life of each and every newborn infant should be saved if it is within your ability to do so?", to both pediatric surgeons and non-surgeons separately.[219] In the pediatric surgeons group, 39% of the Catholics, 13% of the Protestants, and 3% of the Jewish surgeons answered in the affirmative. But the same question addressed to the non-surgeon pediatricians elicited a somewhat different result. In this case the affirmative percentages were: Catholic 29%, Protestant 17%, and Jewish 36%. Clearly, whereas in the first group Catholics are the most "conservative", in the second group it is the Jewish pediatricians who are the most conservative.

In the survey by Todres, et al., two cases were given to the pediatricians, one involving a baby with Down's syndrome with duodenal atresia and the parents refusing surgery, the other involving a baby with severe meningomyelocele (spina bifida) in which the baby was paraplegic, incontinent and faced a high risk of hydrocephalus developing.[220] The answers to a question about whether they would recommend surgery in these cases demonstrated several things about the influence of religion. Regarding the Down's syndrome baby (for whom 46.3% recommended surgery), Catholic and religiously more active physicians, regardless of denomination, recommended surgery more often than Jewish or religiously less active physicians. As well, Catholic physicians were significantly more likely to persist with the decision to recommend surgery even in the face of parental decisions to the contrary. Regarding the baby with severe spina bifida (for whom 33.3% recommended surgery), religiously more active physicians recommended surgery more often than religiously less active. However, in this case those with Catholic affiliation were not significantly more in favour of surgery than were Protestant or Jewish pediatricians.

The Todres survey concludes that while religious affiliation is a significant predictor of decision-making for the baby with Down's syndrome and atresia (66% of Catholic physicians recommending surgery, 50% of Protestants and 38% of Jewish), the degree of religious activity rather than specific religious persuasion was the only significant predictor in recommending surgery for the newborns in both cases. The physicians who perceive themselves as most active were more likely to recommend surgery than those less actively religious.

Todres, et al. provide a plausible interpretation as to why religious affiliation is more significant regarding the Down's syndrome baby than the severe spina bifida baby. They suggest that the reason why Catholic pediatricians were not significantly more in favour of treating the spina bifida baby than were those of other religious affiliations is that by applying the ordinary-extraordinary treatment distinction, a distinction particularly operative in Catholic medical ethics, surgery for the spina bifida child was judged to be extraordinary. But the stronger and more tenacious recommendation by Catholic pediatricians for surgery for the Down's syndrome baby can be explained (argued the Todres' study) by the greater emotional and theological support provided by the Catholic faith to those involved in the birth of retarded children. Todres, et al., refer in this regard to the Catholic faith providing (to parents) absolution of "guilt" on the birth of a retarded child.[221] But in our view a more plausible explanation as regards physicians might be that Catholic theology, as indicated above, insists upon the worth, dignity and equality of the retarded.

They also suggest an interpretation for the relatively low percentage of Jewish pediatricians recommending surgery for the child with Down's syndrome and atresia. As already indicated above, the Jewish theological position tends to be the most conservative in the matter of supporting and maintaining life. In the view of Todres, et al., this result indicates that that position, one particularly identified with Orthodox Judaism, is simply not adhered to strictly by many non-Orthodox Jewish physicians.

Crane's survey comes to somewhat similar conclusions about the influence of religion, but provides some interesting variations as well. Among pediatric heart surgeons, Catholics were the most likely to say that they would operate on physically damaged children, but liberal Protestants were the most likely to respond that they would operate on brain-damaged newborns (though the percentage differences were not large in either case).[222] Interestingly, the least religious pediatric heart surgeons (of all religious affiliations) were most likely to say they would operate, a result seemingly at variance with that found in the survey by Todres, et al.

Among pediatricians other than heart surgeons, the proportions of active physicians (i.e. likely to provide treatment, and on physiological rather than social grounds) were highest among Catholics and Asians and lowest among liberal Protestants, in treating and resuscitating salvageable newborns. As for pediatric residents, Catholics and Asians were the most likely to be active in resuscitating salvageable newborns, and Protestants the least likely, but no significant differences appeared between these groups in the treatment of these newborns.

Crane concludes her data on the influence of religion and religiosity with the following observation about physicians generally:

> It is interesting to note that their behaviour remains distinctive in this area even when they are not very religious and are not guided by official church doctrines in these matters. Consequently the role of religiosity appears to be less important than religious affiliation, which seems to provide those who have been exposed to it (even if they no longer seriously practice it) a perspective on these issues that is remarkably consistent. Thus there is some indication that the [medical] activism of the Catholic is more ritualistic in its motiviation ... while that of the Jews appears to be more humanitarian. Liberal Protestants are less concerned than either of these two groups about the preservation of life except when the individual expresses the desire to live. In this respect, identification with a religious group is much more significant than generational, social class or sex differences.223

iv) <u>Social qualities of life as treatment criteria</u>

But what of the influence of <u>social</u> quality of life considerations on treatment decisions, for example these: the impact of a seriously disabled child's survival on the family, the family's marital and economic status, the financial burden on the family, the financial burden on the state, the availability of support services and institutions, the child's usefulness, and so forth? And how does religious affiliation relate to these social values of the physician?

We will deal with the second question first. Of the available surveys of pediatricians only that of Crane relates religious affiliation to social quality of life criteria and both factors to that of the pediatrician's readiness to treat or resuscitate. First of all, the survey establishes a clear relationship between the pediatrician's views about social quality of life factors and their treatment activism. Those concerned with the disabled newborn's usefulness to and impact upon the family, or usefulness to society and financial burden on the family, were likely to be less active in treatment and resuscitation.[224] A major influence on the pediatrician and the degree of activism is whether the pregnancy is "precious" to the mother. Especially this last factor allows Crane to conclude that at least among pediatric residents, cultural background (Eastern citizenship, Western citizenship) has more influence on medical activism than does religious background. That emerged clearly from the great importance given by physicians to the fact that a pregnancy was "precious" to the mother.

Still on the question of the relationship of religion to social quality of life factors, Crane's survey also indicates that the economic situation of the parents, did not appear to significantly affect decisions by <u>Protestant</u> and <u>Asian</u> pediatricians to treat or resuscitate a severely physically damaged child. Jews and Catholics, on the other hand, were most influenced by this factor.[225]

As for the impact or influence of the various social or contextual quality of life factors on pediatric decision-making, all the surveys assign considerable influence to some of these factors. This is especially so for cases when physicians are uncertain on purely physiological grounds how actively to treat an infant.

The Crane survey for example presented pediatricians with seven "social characteristics" of seriously disabled newborn patients, and asked them to rank those which were among the top three as regards influencing their decisions. Eighty percent gave first place to the "impact of the child on the family", 66% to the "child's potential usefulness", 62% to the "precious pregnancy" factor, 49% to the mother's attitude toward a severely defective infant, 42% to the mother's attitude toward a mongoloid infant, 38% to the financial burden to the family, and 14% to the financial burden to society.[226]

As regards the influence of the family's socio-economic status specifically, the Crane survey asked the question by way of a comparison of two possibilities. The first involved 20 year-old parents, neither of whom have completed high school, the second involved parents who were well educated and financially comfortable. Regarding the first couple, 45% of pediatricians said they would treat very actively a physically disabled newborn, whereas the figure rose to 65% who would actively treat the physically disabled newborn of the well-educated financially comfortable couple.[227]

The pediatricians who responded to the Shaw survey provided the following ranking of influences in decisions to allow severely disabled newborns to die: 86.3% listed "potential quality of life", 44.7% listed "infant's probable I.Q.", 40.0% listed "possible adverse effects on the family", 9.0% listed "parents' willingness to raise the child at home", 2.6% listed "cost to society".

As for the Todres survey, one of the questions was the following: "Should any of the following factors enter into your decision to 'run slowly' or 'take heroic measures'?"[228] The criteria end responses (listed in the order of their influence) were as follows:

	Yes (%)	No (%)	No Answer (%)
Parents willing to take care of the child within the family	63	25	12
Economic and psychosocial support for the family	43	34	23
Adequacy of state institutions if parents refuse child	36	40	24
"Priorities" of other patients with better prognosis	30	41	29
Family finances	28	50	22
Feelings of hospital care-taking staff	14	54	32

Though it does not provide the sort of quantitative and statistical information provided by the Crane, Shaw and Todres surveys, the interviews and responses conducted and reported in Canada by Magnet in 1979-80 tend to confirm the picture provided by those surveys.[229] One of the influential considerations referred to by many was the marital status of the baby's parents, in the sense that the disabled child of a young, single unwed mother would be less likely than others to be given life-saving treatment. Another factor of concern to physicians in those interviews was the "quality of the child's family", that is, their intelligence level and psychological adaptation. As one neonatologist put it:

> There is no use in sending a baby back who requires complicated management and care to a mother who is unmarried, who has an IQ of 70 and quite unable to deal with it. She may have part-time work or something like that, or six other kids in the family. We know its not going to work...[230]

Other "social" quality of life factors referred to by those interviewed were: the effect which the addition of a disabled child is likely to have on a particular family (i.e. guilt, mutual recrimination, strain resulting from care and hospitalization, the effect on other children); the economic burdens on the baby's family (children of financially comfortable families have better chances of being treated);

the ability of parents to have additional children (if more children are not likely for one reason or another, medical intervention is sometimes more aggressive).

Most of the social or contextual quality of life factors referred to by respondents in these surveys and interviews are also identified as influences in medical literature generally.[231]

In view of the views, statistics and practices indicated in this section, it seems safe to conclude that the most influential normative approach in pediatric decision-making about disabled infants is somewhere between a consequentialist system and what we referred to above (pp.197-198) as a qualified deontological system.

Given the large percentages of pediatricians strongly influenced by the presence or absence of mental retardation in disabled newborns, the dominant normative system is arguably more consequentialist rather than deontological. The qualified deontological approach we are proposing as most representative of the Judeo-Christian tradition and bioethics, places a high value on the sanctity of a retarded child's life, and on the need to treat them equally. There is every indication in the views and trends identified above that the seriously disabled child who is mentally retarded is seen as meriting equal care and protection even if at considerable cost to individuals and society.

One finds in the views and trends about social or contextual quality of life criteria further signs that the implicit normative system at work is consequentialism. The most influential branch of that approach is in some instances that of <u>social</u> consequentialism (which measures the value of a life and life support against the consequences for the quality of life for others) rather than <u>personalistic</u> consequentialism (which measures the value of life and treatment against the consequences for that individual child's quality of life). The strength of criteria such as likely impact of the child on the family, the potential usefulness of the child, the economic status of the child and the potential impact on other children suggest that the quality of life of others is in some respects at least as influential as the quality of life of the disabled child.

It should not of course be assumed that factors such as family finances, impact on family, and willingness of the family to have and care for the child can be divorced from the child's expected quality of life. Quite obviously many seriously disabled newborns with a multitude of problems (for instance a spina bifida child who might have serious renal, neurological and bowel problems, paraplegia and mental retardation) will require expensive and continual care, and if returned to a home without the needed resources and readiness and ability to sacrifice, that could have devastating effects on both the child's quality of life and that of the family. Clearly those factors must be considered and weighed

But according to the normative bioethical system we have proposed as normative, those social quality of life criteria should not be the decisive factors, at least not for the life-saving treatment decisions themselves. The importance and influence of those factors should be on the question of what to do with the child after treatment, whether to place the child at home or in an institution, and if the latter, which one. On a more long range basis they should also influence concerted efforts to provide better or more humane chronic care institutions when the existing ones are judged inadequate. Those factors should influence our readiness as a society to re-order our priorities by providing the needed resources and care even at some sacrifice.

But the decision to treat or not, to save that disabled life or not, should normally be made mainly on the basis of the medical and physiological diagnosis and prognosis. In the exceptional case, the child's present problems and expected quality of life given those problems will not justify even life-saving treatment. From the trends and views identified above, one can only conclude that for the majority what should be the exceptional may be in danger of becoming the ordinary.

Transposed into the ethical language of rights, claims and interests, one is left with the conclusion on the basis of some of the trends identified above, that all interests or claims of various parties are too readily and uncritically assumed to be rights, and rights all having more or less the same weight. The newborn child's right to life will of course sometimes conflict with the interests, needs or claims of the parents, other children in the family, society and so forth. But it is in our view quite wrong to assume that all those claims and interests of other parties, for instance to be free of burdens and anxieties, are necessarily rights and rights of equal weight with the infants' right to life. Particularly from the perspective of the Judeo-Christian deontological normative system, the claim of others (whether individuals or society generally) to be free of burdens, cannot be respected even at the cost of taking another's life by act or omission.[232]

B. Parental wishes - too often decisive

Both medical literature and surveys demonstrate that the wishes of the parents to have treatment provided or withheld is the most influential of the social or contextual quality of life considerations in these treatment decisions. That is especially the case when the disabled infant is also retarded. Gustafson reports a case in which the parents refused to permit the surgical correction of an intestinal blockage in their newborn son diagnosed to have Down's syndrome (mongolism). The physicians had explained to the parents that mongolism is one of the milder forms of retardation, that they are almost always trainable and able to hold simple jobs and are generally happy children, but that if the intestinal blockage is not corrected the child will die. They continued to refuse permission and the child was allowed to die by starvation. He went on to report this conversation with the physicians involved:

> When posed the question of whether the case would have been taken to court had the child had a normal IQ, with the parents refusing permission for the intestinal operation, the near unanimous opinion of the doctors was: "Yes, we would have tried to override their decision." Asked why, the doctors replied, "When a retarded child presents us with the same problem, a different value system comes in; and not only does the staff acquiesce in the parents decision to let the child die, but it is probable that the courts would also. That is, there is a different standard.... There is this tendency to value life on the basis of intelligence ... [It's] a part of the American ethic."233

In assigning weight to the wishes of parents, physicians have essentially three theories of parental authority to choose from or combine. The first is that parents in effect own their children and that it is therefore within their rights to make any decisions affecting them, no matter what the justification or results. In the views and data to be summarized in this section, there is no evidence that physicians are prepared to grant total autonomy and discretion to parents for life-threatening treatment decisions.

A second theory is that which sees parents as "trustees" over the infant, or as proxies for the infant, entitled to autonomy up to the point that the infant's interests, in this case its life and health, or at least its "life worth living", are not threatened by the parents' wishes. Clearly many physicians, if not most, would explicitly subscribe to this theory. But the real issue in some cases is precisely what is in the infant's best interests, whether the life at issue really is "worth living", and whether in a particular case the interests of a child should give way to the interests (or rights) of parents. As already indicated, the disabled infant's interest in living tends to take second place to the parents' interest and wish that the child not survive when that infant is mentally retarded. As such, the implicit stance of many physicians on the matter of parental authority which emerges from the views and data above and below seems to be closer to the first theory (the granting of total or near total discretion and autonomy) than may be explicitly acknowledged or realized.

At the same time, given the physician's own views about mentally retarded newborns already summarized above, acquiescence with parental wishes that (for example) a Down's syndrome infant with atresia not be treated, may be as much an expression of the physician's own views and preferences as a granting of parental autonomy in decision-making.

A third theory and choice regarding parental authority is one which holds that parents should not be involved at all, or only minimally, in life or death treatment decisions for their disabled infants. A variety of arguments are made in justification of such a policy, some of them claimed to be in the interest of protecting the parents, some in the interest of protecting the child. In the former category, it is argued that parents are likely to suffer from intense guilt whatever they decide, or that life or death decisions will cause too much anxiety. In the latter category it is argued for example that parents are too emotionally involved to make objective decisions in the child's interest, or unable to understand the complex information needed to make an informed proxy decision in the child's best interests.

The various surveys available suggest that most pediatricians and neonatologists give much weight to parental wishes, even for life and death treatment decisions. The questionnaire by Todres, et al. included several questions directly related to this matter. In answer to the general question, "Should informed consent include the right of parents to withhold consent for surgery?", 79.6% of the physicians answered in the affirmative. Given the specific case of a Down's syndrome infant with atresia, the parents refusing treatment, 46.3% of the physicians recommended surgery. But of that percentage, only 40.2% would pursue a court order to authorize surgery over parental objections, and 54.2% would not. Five and six-tenths percent did not answer the question. Of those who would not pursue a court order, the majority would attempt to convince parents to agree, but if not successful would go along with them.[234] All of which leads to the conclusion that 78% of the physicians questioned would abide by the parental refusal.

The same survey presented physicians with another specific case, that of a baby with severe meninogomyelocele (spina bifida). In this case, 33.3% of pediatricians recommended surgery, but 60% of that group would change their position if the parents withheld consent for surgery.[235]

The survey by Shaw, et al. found that 85% of physicians would follow parental wishes not to treat an infant with Down's syndrome and congenital heart disease.[236] The report on the survey adds that 7% of those who would acquiesce would argue for operating on the infant (i.e. save its life) when the parents were "ambivalent".

The generalized acceptance by physicians of the importance of parental wishes is evident in the official position of the American Medical Association. In 1982 it stated in part:

> In desperate situations involving newborns, the advice and judgment of the physician should be readily available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents....237

Is a better alternative to the routine acquiescence with parental wishes, that of not informing or involving them at all? Not in our view, and certainly not in the view of physicians such as Duff and Campbell, who insist upon the role and right of parents to be informed and share in decision-making about their newborn infants.[238] They and others are undoubtedly right to chastize those physicians who as a matter of standard policy do not disclose to parents the full picture of their disabled infant's condition, the implications of treatment and non-treatment, and exclude them from decision-making and/or disregard their views.[239] The parents are, after all, the parents of that child, and they will have to live with the consequences of life and death treatment decisions whether or not the infant remains in their custody.

While in some instances it is undoubtedly true that full disclosure and involvement in the decision would be an excessive burden for the parents either during or after the decision, the empirical and other evidence for the various alleged harms to parents is too weak to support what is often only paternalism. As noted, one such argument advanced in order to exclude parents is that if permitted to participate in these decisions they could easily suffer intense guilt if the infant dies, or if it survives with severe disabilities and pain.[240] It is of course equally likely that parents would feel guilt about the outcome if they were not informed and involved. But more substantially, it may not be either desirable or possible for physicians (or others) to attempt to protect parents from the consequences of their decisions. That is after all the essence of paternalism.

Another often paternalistic argument for excluding parents is that it would cause them too much anxiety or grief But grief is not in itself something to be protected from. Up to a point it is a natural, healthy and inevitable reaction to a very difficult event, whether the infant is allowed to die or survives with serious handicaps. Rather than protecting from grief by denying parents their right to be involved, physicians and others have an important role to play in providing needed emotional support and information. Some recent studies indicate that parents who are involved in these decisions in fact do not experience more guilt, anxiety and depression than those who did not participate.[241]

The third of these paternalistic arguments is that parents are too upset to decide objectively.[242] While that is undoubtedly sometimes the case, there is no evidence to establish that it is the rule. Here too, some experiences and studies insist that though there will inevitably be some initial shock and confusion, most parents, if sensitively and carefully informed and supported, can make rational decisions.[243] Implicit in this argument to at least some extent is the assumption that the physician, unlike the parents, does always decide rationally. But as many physicians know all too well, they too have their emotions and feelings to contend with, and their personal value preferences. As well, the diagnostic and prognostic evidence upon which the physician relies to make "objective" decisions for or against treatment is often far from reliable. By general consensus, progress and predictions about the extent, and burdens of disabilities, whether they will improve or not and what the expected quality of life of the infant will be, are sometimes far from certain.

But having granted that the usual paternalistic arguments for excluding parents are weak indeed, is not to conclude that the physician should always acquiesce in parental wishes, and that the physician may <u>never</u> make unilateral decisions. There is quite another, and by no means paternalistic argument which can sometimes support unilateral decisions by physicians, or appeals to courts to authorize going against parental wishes. It involves the physician in his role as advocate of the infant, a role which should come into play when there is a need to protect the interests of his infant patient from the consequences of a parental refusal of treatment or a parental request for treatment.[244] It assumes that, as already argued above, the right of the infant to health and life should sometimes take precedence over the wishes of the parents. That right of the newborn child and the wishes or interests of the parents are not of equal weight. Consistent with the Judeo-Christian bioethics we are using as our norm, the physician's role of infant advocate is based on the premise that there is a presumption in favour of life, and the rule that a life should be preserved unless by exception there are good reasons to believe that treatment and the prolongation of its life would impose excessive burdens on the infant.

The arguments usually made for unilateral decisions by physicians are indeed paternalistic - in effect they amount to protecting parents from the consequences of their decisions by limiting their parental rights and liberty. But to argue that the physician should sometimes act against parental wishes (seeking court authorization when necessary) is not paternalism vis-à-vis the parents, and certainly not vis-à-vis the infant who is incapable of making decisions.[245]

Should the physician's role as advocate of the infant itself be limited and qualified? In our view it very definitely should. Parental rights, wishes and values cannot be casually dismissed, and in most cases there will be a range of treatment (or non-treatment) options from which a parent should be entitled to select and about which parents and physicians will normally agree, none of which will threaten the infant's rights. It will only be in the rare and exceptional case that the parent's wish to let their infant die will be in conflict with the infant's best interests. The best example is that of the Down's syndrome infant with atresia, when parents refuse corrective surgery for the atresia. It is only when those conflicts of interest arise that the parents would no longer be in the best position to decide.

It has been suggested that a further qualification should be attached to the infant-advocate argument. Strong for example supports the advocacy role and unilateral decision-making by physicians for the circumstances indicated above, but argues that it ought not to apply "when it is reasonable to believe that saving the infant's life would cause great hardship for the family".[246] But we do not agree. In our view that exception is untenable and in effect risks undermining the whole point of the physician's role as infant advocate.

In the first place, even a mildly retarded Down's syndrome child might not then qualify for surgical correction of his atresia, because some parents would feel that caring for this child for the rest of his life would involve "great hardship". They may well be right in so judging, both in absolute terms and relative to their particular circumstances. It is arguable that almost <u>any</u> seriously disabled child will cause great hardship to their families. Some families can cope with that and others cannot or do not wish to. It is at least partly <u>because</u> many families opt for non-treatment of disabled newborns (for whom treatment is indicated) on the grounds that they cannot or do not wish to assume the great hardship of caring for that child, that the physician's role as infant advocate can (by exception) justify his unilateral decision in favour of treatment. But if great hardship to the parents is to be an exception to the physician acting as infant advocate, then the justification itself is removed.

Secondly, in proposing an exception to life-saving treatment based upon great hardship to parents, Strong and those physicians who implicitly agree with the exception, are in reality giving precedence to an interest or claim of the parents over the right to life of their child. One senses this assumption even in the way the question or conflict is posed by Strong:

> When there is evidence that the infant will probably be handicapped, the neonatologist often faces a conflict between a duty of <u>nonmaleficence toward the patient</u> and, since aggressive treatment of the infant may result in serious harm to the family, a duty of <u>nonmaleficence toward parents</u> as well. How is the conflict to be resolved?[247] [Emphasis added]

Here the question is posed as if the two duties are of equal content and therefore equal weight, but if one adds as we must that the "duty of nonmaleficence" to the infant is that of not unjustifiably allowing it to die, whereas the duty to parents is that of not unjustifiably imposing hardships, the duties do not appear to be equal at all. Strong goes on to conclude:

> ... there appear to be no sound reasons for thinking that the duty of nonmaleficence toward the infant has priority. In the absence of such reasons, it seems reasonable to conclude that it is at least permissible to give priority to the duty of nonmaleficence toward parents.[248]

But as already suggested above, no compelling arguments exist which establish that parents have a "right" to be free of hardships - what they have is more arguably an "interest" in being as unburdened with hardship as possible. Furthermore, especially from the perspective of the Judeo-Christian bioethics serving as our standard, the right to life of an infant for whom life-saving treatment is indicated, ought to take precedence over lesser claims and interests of parents and other parties, even at the cost of considerable hardship to others. That, surely, is the real thrust and duty of the Judeo-Christian bioethics we have described and proposed.

But to so conclude regarding the "great hardship" issue, is not to imply that parents must always be obliged to themselves care for their disabled child because they cannot or do not wish to accept the burdens of care involved. That such burdens can often be bearable and even rewarding is a fact of experience,[249] but it is equally a fact of experience that some parents are not equipped financially, emotionally or otherwise, to deal with the supervision and sometimes constant care which will be required. In such cases alternative custody arrangements should be offered and provided, often that of institutionalization. In other words, the treatment of a disabled infant need not and should not automatically imply as a consequence, parental custody.

Alternatives to parental custody, in the form of adequate and humane institutional placement, adoption or foster care, are admittedly not always immediately available. But rather than use this fact as an argument for non-treatment,[250] it argues instead for a societal need to re-order our priorities to make available more, and more humane, custodial institutions for these children, and for a greater readiness on the part of other families to accept them as foster or adopted children.

What is fundamental, however, is that the treatment and custody decisions be separated, and that the former not depend upon the latter. One physician (Fost) correctly expressed that need and policy as follows:

> In Dr. Duff's institution, <u>custody</u> and <u>care</u> decisions seem to be fused. In the institution where I work, an effort is made to see these as separate, although related, decisions. This attitude allows more time for reflection, so that parents may say "yes" to medical care for their child, a decision which has to be made in a short time, and then take more time to decide whether or not they can support the child in their own home. Separation of these decisions also acknowledges that parents who emphatically say "no" to custody may not be the proper advocates for the child in decisions regarding care.[251]

C. Caring when curing stops - too often overlooked

The next test to be applied to physician views and practices is this: when a decision has been made not to therapeutically treat a seriously disabled infant, does "caring" in the absence of curing remain a priority? More specifically, what forms of care are considered to be "ordinary" when efforts to cure have been abandoned and the infant is allowed to die? One obvious option at this point is that of (active) euthansia, which will be considered in the next section. We will conclude that euthanasia is viewed unfavourably by the vast majority of physicians.

As indicated several times earlier in this thesis (e.g. pp. 174-175), the abandonment of efforts to cure a disabled infant should never, from the perspective of the bioethics serving as our norm, imply the abandonment of the infant himself or herself. Fidelity, love and respect continue to be owed to that infant. That should include efforts to make whatever length of time remains as comfortable and unrestricted as possible, without unreasonably prolonging suffering or the dying process. In some instances this goal of caring, not curing, may even justify surgical intervention for palliative purposes. That would especially be so if the infant in question is expected to live for some time.

There is (not surprisingly) considerable ambiguity and hesitation in the views expressed by physicians as to what forms of care should and should not be provided to infants being allowed to die. Some physicians who have written extensively on various aspects of treatment decisions for seriously disabled newborns, say little or nothing about the specifics of care once a decision not to treat actively has been made. Duff and Campbell for instance would seem to fall into this category. As we will show in the next section, they clearly wish that active euthanasia was a legally acceptable option. But they are more or less silent or ambiguous as to how they handle these cases at present or how they should be handled.[252]

Few surveys directed to physicians have explored their opinions and practices on this matter. One which did is that by Shaw, et al. That questionnaire asked the following question:

> If you accept parental withholding of lifesaving surgery ..., would you (a) stop all supportive treatment including intravenous fluids and gastric suction; (b) give oral feedings; (c) terminate the infant's life actively by an injection of drugs such as morphine or potassium; (d) insist that the parents take the baby out of hospital if no treatment is to be allowed?[253]

The responses of the pediatric surgeons (SG) and other pediatricians (PG) to the questions on p.238 were the following (in percentages);

	SG			PG		
	Yes	No	No Answer	Yes	No	No Answer
(a)	63.3	19.5	17.2	42.6	26.8	30.5
(b)	30.7	36.0	33.0	18.4	42.6	38.9
(c)	0.4	61.0	38.6	2.6	55.3	42.1
(d)	7.9	56.9	35.2	8.4	50.5	41.1

Leaving aside until the next section the responses to (c), i.e. regarding active termination of the infants' lives, several aspects of the other responses merit some comment. It is first of all surprising that so many in both groups gave no answer to the questions. Shaw, *et al.*, suggest this may be due to an unwillingness to generalize about clinical situations in which each case has some unique characteristics, an at least plausible explanation. But it is arguable that at least to some extent the non-answers are due to the physicians not having adequately faced or resolved this matter of how to deal with infants once life-saving is abandoned.

There are also some fairly wide differences between the pediatric surgeons (SG) and the other pediatricians (PG) regarding questions (a) and (b). While the largest proportion of both groups prefer to discontinue both supportive care (including presumably pain-killing drugs and intravenous nourishment) and oral feeding, a larger proportion of pediatric surgeons would discontinue general support but continue to give ad lib oral feedings. The comments accompanying the responses suggest some uncertainty and disquiet. Some for instance felt that a minimal level of supporting care is necessary, such as intravenous fluids. But several gave as their reason that this would ease the stress on the staff. As one physician put it, "Some supportive care must be needed if the attendants in the unit are to be considered. Withholding support is hardest on those who care for the infant from day to day".[254] A few others indicated that they would provide such support when necessary to minimize the infant's terminal distress.

While we cannot be certain, question (a) would seem to necessarily include pain-killing drugs in the expressions "supportive treatment" and "intravenous fluids". If that is so and if that is how the physicians understood the question, then the largest proportion of both groups appear ready to withdraw even supportive treatment to control an infant's pain and suffering, a surprising and disconcerting result to say the least.

Another study of physician attitudes and practices which touches upon this matter is that reported on by Magnet.[255] On the basis of his interviews he concludes that there is both some consensus, and much doubt:

> The consensus is that the baby should be fed, kept warm and made comfortable. His fluids should be managed. Beyond this, nothing should be done. No resuscitation should be attempted. No minor surgery should be performed. No antibiotics should be administered...256

But he goes on to note:

> Although most doctors accept the logic of this consensus, they find it difficult to implement. Practicing by these rules brings doctors face to face with their inability to assist or cure. To some it appears indistinguishable from euthanasia.257

D. Active euthanasia - too often acceptable

The next of our tests to be applied to the views and practices of physicians is that of whether or not they reject (active) euthanasia as an option. As we argued several times earlier in the thesis (e.g. pp.164-165), to kill an infant for whom aggressive or therapeutic treatment is no longer indicated would be the most serious expression possible of disrespect for the sanctity of human life. While according to a strictly utilitarian calculus, killing such infants could sometimes be considered beneficial to them, such a policy would violate deontological Judeo-Christian bioethics and could put the sanctity of all human life at risk.

Surveys of physician attitudes indicate that the large majority do not favour active euthanasia as a policy and do not practice it. Crane's survey for example included a question about the direct killing of an anencephalic newborn.[258] The responses were overwhelmingly negative, only 1% saying that they would be likely to give an intravenous injection of a lethal dose of potassium chloride or a sedative drug to such an infant. Only 3% said that they might do so. Crane concludes:

> The data suggest that while negative euthanasia ... is widespread, positive euthanasia is relatively rare. In fact there appears to be a very strongly held norm in the medical profession against direct killing, even when the individual has no capacity whatsoever to develop social relationships ... On the other hand, close to half the internists said that they would be willing to increase the dosages of narcotics for a terminally ill cancer patient to the point where it would probably lead to a respiratory arrest.[259]

As already indicated above (p.238) the survey by Shaw, et al., also included a question seeking physicians' views about various options for disabled infants no longer being treated therapeutically. One part of the question asked whether they would terminate the infant's life by an injection of drugs such as morphine or potassium.[260] The responses from the two groups questioned, pediatric surgeons (SG) and other pediatricians (PG) were as follows (in percentages):

SG			PG		
Yes	No	No Answer	Yes	No	No Answer
0.4	61.0	38.6	2.6	55.3	42.1

In this case the rejection of euthanasia as an option does not appear to be as overwhelming and clear cut as the results reported by Crane. Very small proportions answered in the affirmative, but surprisingly large proportions of both groups did not provide a yes or no - 38.6% and 42.1%. What that means is impossible to say. Possibly at least a part of those proportions represent physicians who have not made up their minds on where they stand in principle, some may not have any experience with having to make that kind of decision in practice, others may answer one way for one kind of case, another way for a different case. Whatever the numbers mean in fact, they at least imply that a large proportion of those physicians questioned may not have rejected active euthanasia in principle and without exception as an acceptable option.

Still another survey, that of Todres, <u>et al</u>., provides some support for that interpretation of the Shaw survey's findings, in that 32 percent of pediatricians thought that a law should be passed making the killing of infants a legal act under certain conditions.[261]

An unpublished study of pediatricians in the New Haven, Connectiticut area, referred to by Duff and Campbell, apparently found that active euthanasia was acceptable to many of them.[262] It was "viewed favourably" by 39%, with mixed feelings by 28%, and opposed by 33%. In other words, according to that poll, 67% of those questioned do not oppose active pediatric euthanasia without reservation. Duff and Campbell added that, "There was a relationship between pediatrician performance ratings and attitude - the higher the rating, the more likely the attitude toward euthanasia would be positive".

Without supplying any figures and percentages, Magnet claims that two types of active pediatric euthanasia can be documented.[263] One is by increasing the dose of pain-killers for purposes of pain-killing, the baby's death being thereby hastened as a "side effect". But in our view this could only be characterized as killing since killing, and not just pain-killing, is intended and caused. That would be determined from the legal and medical perspectives by ascertaining if possible whether the dosage given was well beyond that needed for pain-killing purposes. If not, even if death is hastened, as long as the dosage was within acceptable limits for the pain and problem involved, that is not killing. The second type of euthanasia Magnet claims can be documented is that which involves saving up the individual dosages of morphine prescribed for an infant, then administering them in one lethal dose. He acknowledges, however, that "it is impossible from my survey to say how common is the second situation ... It appears not to be unusual in terminal cancer wards. However neonatologists surveyed were reticent about discussing this. Some cases were described at second hand".[264]

A recent case in Canada which involves administering a lethal dose of morphine to a severely disabled infant, was that of the Candace Taschuk baby in Edmonton, Alberta. In that case the physician involved admitted prescribing a lethal dose of morphine, which was administered by the nurse on duty.[265] Though the child died several hours later, a fatality inquiry later ruled that the cause of death could not be determined. The physician was charged with homicide, but fled the country and returned to his homeland. Testimony at the subsequent inquiry included testimony by nurses that doctors will sometimes order small doses of morphine knowing it shortens a disabled infant's life.[266] But that need not mean that those physicians are actually killing those babies. As indicated above, the <u>knowledge</u> that the infant's life might be shortened does not make the action legally, medically or ethically "killing", as long as that dosage is reasonable for controlling the suffering of that infant.

Though the majority of physicians undoubtedly would not and do not practice active euthanasia on disabled infants at present, it would seem that some do not do so mainly because the law presently prohibits it, not because it is against their religious or other convictions, and they would like to see the law in this regard changed. It is doubtful that these physicians constitute a majority, but the number may be considerable. As indicated above, the Shaw survey found that 32% of the physicians questioned thought that the law should be changed to permit pediatric euthanasia under certain conditions. Duff and Campbell are clearly of the view that it should be decriminalized, and imply that they and others do not practice it at present only because it is illegal.

Duff and Campbell provide a strong hint that they favour active euthanasia already in their first and most influential report of 1973, in which they refer somewhat obliquely to seeking "early death as a management option".[267] In a subsequent article in 1976, they imply that physicians may in fact sometimes practice euthanasia and rightly so, but because of legal fears they do not talk about their views publicly. They write:

> We believe that "deep down" almost all physicians and those they serve would agree that there are some occasions when death may be a prudent choice and achieving death (in fact, killing) a sorrowful and painful obligation. At the same time they may support the argument put forth by Rachels that there is no moral difference between active and passive euthanasia ...

> physicians are reluctant to admit these views ... They may fear speaking out against the law ... at least a substantial minority of persons believe doctors secretly and rightly practice selective euthanasia.268

Later in the same article we read:

> Thus, we believe that choices for death, whether by active or passive means, should be permitted ... It seems evident that suffering patients (when able), sorrowing families, and concerned physicians have always sought the least detrimental alternative while deciding care in the face of tragedy. Sometimes, despite the law, they have chosen an early death by passive or active means as was required in the varied situations. There is a need in our society for a policy of deciding care according to individual situations as the parties most involved feel is correct.269

In still another article several years later, Duff and Campbell noted about patients, families and health professionals, that:

> Sometimes they felt obliged to abandon the comfortable, conventional morality of Ramsey in favor of the less orthodox and less comfortable positions of Joseph Fletcher and Daniel Maguire. They believed that there was a time and a reason to choose death and a justification for deciding the mode of achieving it.270

Finally, Duff and Campbell argue that non-treatment alone can leave an infant worse off than before, and when that is so active euthanasia should be allowed:

> Reasoning about the most severe forms of spina bifida often goes as follows. Without treatment, the child may die, or live, but in a more miserable way than if he were treated. With treatment he will probably live but his disease and treatment may be so great a burden to himself and his family that the family and all advisors feel the best moral choice is to kill the baby. The awesomeness of this seems exceeded only in the claim that the choice need not be faced by people who care.271

In conclusion, while available data and views suggest that only a small minority of physicians are likely to practice pediatric euthanasia, a larger proportion (though by no means the majority) appears to consider it a desirable option in some cases, but one not practiced largely in view of its illegality, an illegality they would like to see abolished. If that is so, then for that proportion of physicians (e.g. 32% according to one poll, 39% according to another) the influence of our normative Judeo-Christian bioethics in the matter of active euthanasia is clearly not predominant. For the proportion of physicians which does not oppose active pediatric euthanasia without reservation, the predominant influence restraining its practice and the public expression of these views is arguably not personal conviction based upon religious (or other) commitments, but varying degrees of fear of apprehension by the law, combined with a risk of tarnishing the healing image of the physician.

E. Conclusions

Based on the views and data gathered above, we can only conclude that in several fundamental respects the Judeo-Christian bioethics we proposed as normative is not as influential upon the views and practices of pediatricians and neonatologists as one might have thought. Applying as we have some of the tests proposed earlier, the normative role of that version of theological bioethics in influencing and shaping treatment policies is shared with and modified by a number of other influences. What emerges as the underlying and implicit normative system for the views and practices of a surprising number of physicians is not an approach to sanctity of life and quality of which we characterized as "deontological with exceptions", and not even "personalistic consequentialism", but "social consequentialism". The latter measures decisions about whether or not to provide life-saving treatment largely by the consequences for others, not necessarily for the consequences to the infant.

In these views and practices there is evident discrimination against the interests and rights of the mentally retarded, even the mildly retarded, whose life-threatening complications are not treated as routinely or as vigorously as are the same complications of those infants only physically disabled. The motive of physicians who adopt this policy is generally that of compassion for both the infant and the family, but parental benefit, interests and wishes are often respected by denying a more fundamental right of that infant to life. Much weight is given in physician views and practices about treating disabled infants to the matter of burdens on parents and families. It is seldom acknowledged that caring for disabled children can be a manageable and even rewarding experience for many parents. As well, the views and practices of many physicians assume that there is more certainty about both the effects on families from caring for disabled children, and about the expected-quality-of-life of various handicaps, than is in fact the case. Rather than separate decisions about care and treatment from those about custody, the former is too often made to depend upon the latter.

The tendency of many physicians and parents to give so much weight to parental desires and burdens, and to be so prepared to allow especially mentally retarded infants to die (or even be killed) implies the fundamental value judgment that (for example) a Down's syndrome child has less intrinsic value than others, may not even be fully human, and that intelligence more than anything else is the basis of the normatively human and of human rights. Whether or not these assumptions are conscious, they are at least implicit in some of those treatment preferences and decisions.

If one instinctively or otherwise believes that an infant child is not fully a person, then of course it is easier to conclude that the infant does not yet have the rights of a person and the claims and interests of others may take precedence. A number of philosophers argue either that infants are not yet persons or only persons in a sort of intermediate or "potential" manner. Tooley for instance writes that infants may well not be persons:

> ... since it is far from clear that human infants possess self-consciousness or that they are capable of envisaging a future for themselves and of having desires about such a future.272

Another philosopher writes that:

> The quality of self-realization of any existing persons should not be sacrificed - to any significant degree - simply in order to allow a potential person [i.e. infants] to develop.273

While there is no evidence in the views and data collected earlier that pediatricians and neonatologists are aware that they hold such views about the personhood of infants, it is arguable that those who are prepared to respect the claims and interests of parents over the right to life of infants for whom medical treatment is otherwise indicated, are in fact implicitly subscribing to at least some extent to these positions about the infant's personhood.

But from the perspective of the Judeo-Christian bioethics we are advocating as the appropriate standard for treatment policies, Down's syndrome babies are humans with the rights of humans. Their claims and rights are not weakened or to be disregarded because of IQ levels or various physical handicaps. Unless an infant is so defective that he has in effect no interests in treatment, or life-saving treatment can be expected to directly or indirectly cause excessive hardship to that infant, his right to life and treatment is not conditioned by his IQ level or the desires of others, but by his very <u>existence</u> and his <u>dependence</u> upon others for the continuation of that existence.[274]

There is no doubt that caring for a disabled infant, whether mentally or physically handicapped or both, puts real burdens on the parents, the family and society generally. But to make these burdens the decisive criterion for or against life-saving treatment as do many physicians is a sign that a fundamental element of Judeo-Christian bioethics has had little apparent impact. Our normative bioethics does not impose on any particular person (e.g. the parents) the obligation to accept excessive or impossible burdens. As stated earlier, if parents are unable to cope, supplementary services or alternative custody arrangements should be sought and provided. But in the final analysis there is little evidence in many of the views about burdens to others collected above that the fundamental Jewish and Christian belief that there is a duty to put self-interest aside and accept burdens for the sake of others, is having much impact. Yet it is perhaps the most fundamental commandment in both Old and New Testaments that "You shall love your neighbour as yourself" (Lev. 19:18; Mt. 22:39), and that, "Each of you must regard, not his own interests, but the other man's" (1 Cor. 10:24).

2. Formal medical policies

To this point in this chapter, we have considered the treatment views and practices of individual pediatricians and neonatologists, as well as the trends and preferences indicated by a number of existing surveys. Those views, practices and preferences constitute "policies" only in the wide sense. While they provided us with more insight into the actual views and preferences of pediatricians generally, a factor too often overlooked by medical, ethical and legal policy-makers, they do not constitute treatment policies in the strict sense.

For our purposes in what follows, we define a treatment in this strict sense as: a relatively coherent, comprehensive and detailed set of normative criteria, and a specific decision-making procedure, designed to protect and promote the interests of the affected parties and to minimize arbitrariness.[275]

We turn now to three examples of policies which at least profess to be comprehensive treatment policies in that strict sense. All three are formulated and used by physicians. Whether they are in fact adequate as policies as just defined and "pass" the normative bioethical tests established above, is the question to be addressed in the remainder of this chapter.

A. The Lorber "early selective treatment" policy

Doctor Lorber, (of the Department of Paediatrics, The Childrens' Hospital, Sheffield, England) has articulated and defended his treatment policy for seriously disabled newborns in the course of many articles and speeches over the past years.[276] He formerly promoted the aggressive and comprehensive treatment of all newborn infants with spina bifida. But he subsequently concluded, on the basis of assessing the long-term results of treating infants over a twelve-year period, that too many of these infants were being treated who would otherwise have died and were as a result surviving with excessive handicaps. He concluded in other words that treatment had swung too far away from the typical earlier extreme of inadequate care to that of treating practically all infants with spina bifida.[277] As he wrote in 1971:

> Intensive treatment of spina bifida cystica in recent years has resulted in a much increased survival rate. More and more infants are being surgically treated. It is felt by some that all affected infants should be operated upon even if it is certain that many survivors will suffer from multiple handicaps ... there are large numbers who are so severely handicapped at birth that those who survive are bound to suffer from a combination of major defects.278

The last part of the above quote provides us with what emerges as the primary humanitarian motivation behind Lorber's selective treatment policy - the <u>suffering</u> of those inflicted with spina bifida. Still more explicitly, he writes:

> If we wish to spare children and their families prolonged suffering and to give better attention to those who are likely to benefit from total care, we may have to select suitable cases for intensive treatment and others for no treatment.279

In our view the establishment of a set of comprehensive selection criteria to serve as normative guidelines for treatment decisions in severe cases is <u>in itself</u> a laudable and needed exercise. By general consensus they may well be especially possible in the case of spina bifida given that findings at birth do appear to provide the basis for at least <u>some</u> degree of prediction about the future medical condition of the child involved. But while the particular criteria and policy proposed and used by Lorber have been widely accepted in clinical practice and adopted by many other institutions,[280] aspects of them including some of their underlying value assumptions, merit serious moral reservations.

First of all then, what specifically is what we have labelled Lorber's "early selective treatment" policy? Though Lorber himself does not do so, we may legitimately divide his criteria and policy into two related parts or levels. The first involves future qualities of life (physical, mental and social) which ultimately make certain levels of defect desirable or undesirable and (consequently) treatment (already at birth) desirable or undesirable. The second part or level of these normative criteria involve the physical or medical criteria which comprise the contra-indications to active treatment in order to preclude having infants survive with an excessive level of defect. It is at the first of these levels that we find (though not in a detailed or rigorous manner) Lorber's value assumptions and considerations. The physical criteria at the second level comprise in effect the "operational policy" following from the quality of future life considerations. Put simply, Lorber's policy could be expressed in this syllogism: Suffering should be minimized, treating all spina bifida infants inhumanely perpetuates suffering, therefore they should not all be treated. Each of the parts to Lorber's criteria and policy merit separate and detailed description before we can apply our normative bioethical tests.

Lorber in effect arrived at his quality of future life conclusions by first of all studying a group of children with spina bifida who had been given total care, in order to show the correlation between on the one hand the type and extent of disabilities now evident some time after birth, and on the other hand the disabilities or medical conditions noted for each child at birth. In his own words, his goal was:

> To correlate accurately observed data obtained on the first day of life with the subsequent progress of the children. Such a prospective analysis would give in any individual baby, with particular signs, probabilities of various severe handicaps and also relatively minor handicap or none.281

In effect, he was attempting to determine the significance of prognosis, to take more of the guess work out of the relationship between prognosis and initial treatment. He concluded that:

> It is possible to forecast from a purely clinical assessment with accuracy the minimal degree of future handicap in an individual even if it is impossible to forecast the maximum degree of disability which he may suffer, if he survives.282

In his summarized results of that first study, Lorber categorizes the quality of the lives of the infants who survived according to the types and degree of physical and mental handicaps. They were grouped into five categories, from gross, moderate and severe to no handicap at all, and a judgment was made as to which categories represent an undesirable quality of life and hence should not have been initially treated. Lorber concluded that those falling within his category of "gross multiple malformations" have an unacceptable quality of life, which treatment could not really have improved and for whom it should not therefore be given. He further concluded that only those falling within the categories of moderate to no handicaps should be treated.

But Lorber does not restrict his quality of life concerns and criteria to the strictly medical or physical factors, and consequent physical suffering, or even to the interests of the child himself. He includes as factors making a level of handicap and hence treatment, acceptable or not, such things as self-respect, capacity to earn, happiness, and prospects for marriage. In his view a handicap, and hence treatment, is unacceptable if one can predict institutionalization, or repeated operations, or having to miss school and frequently be away from home, or face recurring risks of death or restrictions in the opportunities of life. Lorber writes for example, "The worst affected children are those who were illegitimate and others who were immediately abandoned by their families. They live in institutions, retarded and often permanently bedridden. Their chances in life are so unfavorable that the criteria for active treatment should be even stricter."[283]

Some of these criteria, such as illegitimacy or inadequate institutions are clearly "social" quality of life factors. Even more obviously in the "social" category are treatment criteria such as ability to earn their own living in competition with others, the effect they will have on the family, health care personnel and others, and the importance given by him to the cost of treatment.

We come now to the second level or part of Lorber's criteria and policy. Having correlated these findings and quality of life evaluations with the medical conditions at birth, he establishes the physical criteria which will indicate that that newborn will be "selected for non-treatment". He lists six "adverse criteria" each of which is described with much specificity and precision.[284] The first and most important of these is the degree of paralysis and site of the lesion. Another is the circumference of the head. Still another is the presence (along with spina bifida itself) of other gross congenital defects such as heart disease or mongolism.

Lorber maintains that if <u>any one</u> of those conditions is present at birth, even if the infant were treated, the infant cannot survive without severe and multi system physical defects, which will often be associated with mental retardation.[285] Those physical criteria have been supported by many other physicians, and they tend to agree that the meticulous neurological examination involved in applying the criteria would provide accurate predictions about the infant's future ambulatory capability, risks of bladder and bowel complications and hydrocephalus, and other abnormalities.[286]

It should also be noted regarding these adverse physical criteria, that once an infant is selected for non-treatment on the basis of one or more of them, it is clear that all treatment specific to the disorder is meant to stop. In effect Lorber means by selection for no treatment that no antibiotics are given for infection, no intensive care, tube feeding, oxygen or resuscitation, and the infants are fed only on demand.

A major feature of Lorber's policy is that the decision to treat or not should normally be made <u>on the first day</u> after birth and before any therapeutic treatment begins. He does, however, provide some additional criteria by which treatment may be interrupted at subsequent points in the child's development.[287]

Applying his criteria to the infants who had been treated and who were being studied in his 1971 study, Lorber concluded that 116 of 201 (58%) would have been excluded from treatment if those criteria had been applied. In his later 1973 study of 37 infants who did have his criteria applied to them, 25 (68%) were not treated and had died by nine months of age.[288]

Having now described his selective treatment policy and criteria, it remains to evaluate them in the light of our normative bioethical tests. Those tests with particular relevance to Lorber's policy are: the meaning and use he makes of sanctity of life and quality of life considerations, the importance of parental wishes, and whether or not his policy displays adequate caution and self-criticism.

As already indicated above, Lorber does ultimately base his policy on his values, even though to some extent his values are more gleaned by the reader than explicitly revealed by Lorber. His basic value and commitment involves the humanitarian principle of minimizing suffering. And his adverse physical criteria follow logically from his views on what is the minimally acceptable quality of life. That being so, we do not agree with Veatch (and others) that Lorber is applying merely technical criteria, or is only "medicalizing what are really value choices".[289] In our view Spicker and Raye are closer to the mark when they note that,

> ... it will not do to claim that he commits the technical criteria fallacy, for Lorber is well aware of the value-laden basis of his position ... one might say that the entire drive of his newly-acquired and accurate prognoses is to show the systematic connection between these values - e.g. minimize suffering, achievement of a functional quality of life - and their inherence in the six major signs which serve as contraindications for treatment.290

The real question is whether the minimally acceptable quality of life standard which Lorber uses is defensible, not whether there are any value choices behind his adverse medical criteria. In other words, does that quality of life standard underlying his policy promote respect for the disabled infant's sanctity of life, or on the contrary, does it risk sacrificing the life and interests of the disabled infant to the claims and interests of others? Is it unduly pessimistic about the prospects that disabled children can cope adequately or that society can provide more adequate care and institutions? Does Lorber's minimal acceptable quality of life standard in other words risk letting society off the hook by demanding too little change in its priorities? Does that standard risk the foreclosure of future choices by the child itself by forcing decisions to treat or not to be made at birth, based upon values and expectations of those other than that child? In what follows, we will answer all these questions and sub-questions in the affirmative.

Lorber's picture of the quality of life awaiting those infants with adverse criteria should they be treated, is unduly pessimistic and far from being as inevitable or as undesirable as he claims. That he does assume certainty and inevitability is evident in his insistence that a decision for or against life-saving treatment should be made at birth on the first day. But that rule of his policy combined with the exclusive focus on physical criteria makes no allowance for a number of factors which can make an enormous difference to our assessment of an infant's quality of life, and even to the improvement of the disabling conditions. Much depends upon the readiness of parents, health care professionals and society to determine realistic goals and objectives for these children as they grow, and to provide the needed assistance to help them develop their abilities to the extent possible. Those who work with and love seriously disabled children do not generally share the assumption of Lorber and others that there is necessarily any incompatibility between leading worthwhile lives and being handicapped.

Though Lorber claims that most parents of spina bifida newborns accept his criteria and their application to determine whether to treat or not,[291] in fact it is doubtful that most parents are in a position to make an informed decision of that magnitude on the first day. As both physicians and parents have observed, many are in a state of shock on first learning that their child is disabled. What they need is both more information and more time. It is equally a fact of experience that many parents in time "typically learn to value and love their children as they live with them".[292] Adjustment of parents to their disabled child takes time; in some cases it will not happen. But it is not necessarily predictable at birth. As already indicated above, when it is achieved, parental love and sacrifice can compensate greatly for the child's disabilities.[293]

It is arguable on the basis of some evidence that what Lorber takes to be parental concurrence with his quality of life views and physical criteria is often in reality a case of shocked parents accepting the strong suggestions of physicians at the moment when they are most suggestible. The parents are, after all emotionally upset, the mother may have just woken up, and the clear cut solution proposed by a medical authority figure understandably appeals. It is then the physician's view of a "worthwhile life" which is likely to prevail at that point, rather than an eventually more positive view of the parents had they been given time, had the physician informed the parents not only of the potential problems but also of the possible rewards in raising such a child, and had a relationship with their child been allowed to develop. And given that physicians are trained to cure, and tend to interpret chronic and incurable illness as failure, it is regrettable, but should not be surprising, that an infant with serious disabilities which cannot be repaired is often seen as a medical failure and quickly judged to have unbearable burdens with no redeeming features at all.[294]

But still more importantly, Lorber's minimally acceptable quality of life and adverse criteria may not only be foreclosing differing parental values and decisions, but also those of the disabled children themselves. This is especially evident in Lorber's acknowledgement that many of the infants who are not treated according to his adverse criteria would have had normal intelligence.[295] It is especially those children with normal intelligence who, despite their serious physical handicaps, would be in a position to make their own decisions, develop their own abilities and become as independent as possible within their physical limitations. It is therefore particularly disturbing to read that Lorber views the normal intelligence of those children as a liability, as a further justification for non-treatment:

> Using our criteria, some children who would have survived with normal intelligence will be excluded from treatment and will die. Nevertheless, it is my experience, as it is that of psychologists, social workers, teachers and parents, that those young people who are severely handicapped by multi-system defects suffer far more if they have normal intelligence than if they are retarded. Only the intelligent realize fully what they have been through, what they have missed and will miss. Only the intelligent will worry about the frustrations of employment, loneliness, lack of opportunity and of normal family life. Only they will worry about their future and who will look after them when their parents are too old or are no longer alive.[296]

At least two serious objections can be made to that position. First of all, in our view Roy is correct in characterizing it as unacceptable paternalism, on the grounds that:

> The entire thrust of our ... developing civilization has been to ensure that individual human beings have the chance to work out and master their own personal destinies. We have a position here which says that medicine is justified in determining that the working out of some destinies will be too difficult for some persons. Before they have the chance and before they have to face their challenges they may be left untreated and allowed to die.297

But by blatantly substituting his own estimate of what these infants would have wanted if allowed to live, how they would estimate and deal with their handicaps and their lives, Lorber's policy is an extreme example of the dangers and limits in "expected quality of life" arguments applied to newborns. Since the disabled newborn cannot express a personal wish, one is tempted to substitute one's own preferences for the infant's, and the question becomes, "would we prefer this life, with these handicaps, to death?" Since we the non-disabled can never really put ourselves into that infant's shoes, and since each infant is different and unique despite similar physical or mental handicaps, and since the future social context (in terms of availability of care, occupational and schooling opportunities, etc.) is not yet known on the infant's first day of life, substituting our preferences for those of the infant and eventual child or adult can hardly be a reliable guide to deciding what ought to be done now.[298]

Secondly, to be as confident as is Lorber that the choices and destinies of these infants including those with normal intelligence, can be uniformly foreclosed because of predicted suffering, is surely to claim too much for the function of medicine. It is in effect to claim that the legitimate goal and mandate of medicine is that of eliminating suffering and guaranteeing happiness, hardly a claim with any moral or medical roots and credibility. While it may be a quite natural medical "temptation", given the point already made about the difficulties physicians have in shifting to caring when curing is not possible, such a claim cannot withstand critical examination. It should be seen as more in the nature of a professional reflex than the basis of a treatment policy.

It is certainly not the role of medicine to blindly prolong biological life as long as humanly possible. But it is the role of medicine, when it cannot cure, to do everything within its abilities and resources to help those infants to develop themselves and to cope with their handicaps to the extent possible. That would seem to be the proper function of medicine, consistent with its own professional ethics and with the bioethical norms we are applying in this paper.

Still another point should be made about Lorber's quality of life standard. As indicated above, there is a fairly large quotient in his position of what we have branded social consequentialism. That is, along with his primary concern for the interests of the newborn patient, he also gives considerable attention to the interests of others. These concerns include the predicted inabilities of adverse criteria newborns to earn their own living (thus being a burden to society), their impact on family life and family finances, the burden they would place on health care resources and personnel, and the burden on society imposed by the cost of their health care needs.

Two observations should be made about this aspect of Lorber's policy in the light of our bioethical tests. First of all, in allowing these social consequences to form a part of the value basis for his adverse physical criteria, Lorber provides for no clear ranking or priorities of rights and interests. Most importantly, his policy is open to the criticism that the interests and claims of others can take precedence over the right to life of the infant, as if the latter right is at best only equal to the interests of others, or at worst weaker than those interests. As already argued earlier in this paper, that is a moral stance contradicted by the Judeo-Christian bioethics selected as our standard.

Secondly, the social consequences aspect of Lorber's quality of life norm simply assumes the status quo as regards the impact of seriously disabled infants on family, health care resources, institutions and society, and their contributions to the infant. It seems generally assumed by Lorber that as matters now are in that regard, so they always will be, and there is no obligation incumbent on any persons or institutions to re-order priorities, to make greater sacrifices in order to compensate these infants, the weaker, most vulnerable, most disadvantaged members of our society. Lorber's studies could be of much assistance in determining more precisely the health resource needs and costs if more of these adverse criteria infants were allowed to live. But as expressed by Lorber, his policy in effect lets society off the hook. From the perspective of the Judeo-Christian bioethics serving as our test, his policy therefore has a major deficiency. Because he is unwilling to demand more of our society and institutions by way of re-distributing our resources to provide more justly for the needs of our least advantaged members, even at greater sacrifice to us all, he feels compelled to do them a still greater injustice by selecting them for non-treatment and a premature death.

Several aspects of Lorber's treatment policy suggest a lack of sufficient caution and self-criticism, a set of criteria too mechanically applied without first determining some important facts, without subjecting some assumptions to critical analysis. Lorber's policy appears in other words to suffer from what we described above (p.180) as delusions of infallibility.

Some of the features of his policy already discussed contribute to that impression - the too ready assumption that parents share his minimally acceptable quality of life norm, and that the disabled infants selected for non-treatment would have agreed with that decision had they been allowed to live; the lack of time and of any provision for inquiring into the individual wishes of specific parents, at some point after the first day, to keep and care for their child; the lack of time and provision to explore the availability and readiness of an institution to give adequate care to a particular infant should the parents be unwilling or unable to take custody of their child; the lack of empirical or other data to back up his pessimistic and generalized estimate as to the impact of disabled children on families.

Still another feature of his early selective treatment policy supports the conclusion that he has not taken enough care to determine the accuracy of some of the facts on which that policy is based. It has to do with the pain and suffering Lorber attributes to newborns undergoing surgery in the early months. While his position rests mainly on the argument of excessive pain and suffering in later periods - childhood, adolescence and adulthood, he nevertheless frequently refers to the pain and suffering involved in treatment during the first months. That early suffering is directly and indirectly used as a further argument in support of early selection for non-treatment, in that pain and suffering are in effect claimed to be inevitably associated with the aggressive treatment of spina bifida babies.[299]

But this may not in fact be the case. Some physicians who have worked for many years with spina bifida babies report that there is little or no evidence of pain associated with treatment in that earliest period,[300] and some others do not list pain and suffering as one of the features of spina bifida infants who are aggressively treated.[301] Since the basic moral principle behind Lorber's selective treatment policy is that of minimizing suffering, including the pain and suffering supposedly inflicted on actively treated infants in the newborn period, in the absence of more evidence as to the existence and intensity of newborn pain the policy itself cannot be said in that respect to be based on incontrovertible fact.

Another of our bioethical tests to be applied to Lorber's policy is that of whether it provides for continuing care for those infants selected for non-treatment. Since Lorber selects for non-treatment about seventy-five percent of those spina bifida babies brought to him, how are they managed after that decision is made? His stated policy is fairly clear:

> It is essential to state clearly that one hopes that those who are not treated should not live long. It is imperative that non-treatment should really be non-treatment, not just no operation. Nothing should be done to prolong life; no incubators, no tube feeding, no antibiotic drugs and most certainly no resuscitation. It is wrong to carry out palliative shunt operations to make management easier... One should either

> offer total treatment or none at all, other than normal nursing care. The infant should be looked after with gentleness and should be fed on demand. Analgesics, sedatives or anti-convulsants should be used to ensure his comfort.302

Though as already indicated we have serious reservations about the selection criteria themselves, Lorber does appear to acknowledge in principle and practice the ethical rule that palliative care and respect for the (infant) patient remains a continuing duty even when efforts to cure are not undertaken or cease. The policy as outlined would seem to be for the most part justifiable given a decision not to prolong a life judged to be one of excessive hardship - the infant is fed on demand, looked after gently and given sedatives or anti-convulsants for purposes of comfort. But we nevertheless have two reservations about this palliative care aspect. The first has to do with the narrow range of palliative care responses suggested. The second has to do with the way this part of the policy is apparently applied by some institutions using the Lorber criteria.

In describing above the "continuing duty to provide care" test (pp.174-175), it was suggested that this obligation may sometimes include fairly extensive treatment, including even surgery. If the duty essentially means the providing of as much comfort and capability as possible for the period remaining, then to exclude anything "beyond normal nursing care" as does Lorber may well be an unjustified restriction. Even when surgery for the purpose of extending a life has been ruled out, surgery for palliative purposes may nevertheless be medically and morally indicated - e.g. to improve mobility, ease discomfort, maintain muscle activity or improve the prospects for nursing care. One by-product of treatments beyond normal nursing care for an infant selected for a non life-extending treatment, might in fact be the (undesired) extending of that life by weeks, months or longer. But surely that is not to be regretted if the infant was thereby made more comfortable and capable for his brief life.

A second reservation concerns the manner in which palliative care may be practiced by those places applying Lorber's policy. Lorber referred in the quote above to providing infants selected for non-treatment with analgesics and sedatives. There are some grounds for suspecting that the infants are given drugs such as morphine, not to control pain but to keep the babies drowsy so that they will not demand food and so die earlier. It is difficult not to describe such a practice as a form of euthanasia by act or omission. The basis for this suspicion is the fact that hospitals or physicians applying Lorber's selective non-treatment policy tend to report that <u>all</u> those not treated died relatively soon after birth, whereas those with more conservative policies found that the infants not selected for (aggressive) treatment often lived much longer despite getting only palliative care.[303]

A last test to be applied to Lorber's approach is whether it excludes euthanasia as an option. The position adopted earlier in this thesis is the traditional Judeo-Christian one that because life is created by God, not man, it is sacred and cannot be taken by act or omission even if that might in some cases be beneficial to the patient involved. Lorber does explicitly exclude killing infants not selected for treatment, but two qualifications should be noted. First of all, there is the suspicion noted above that "palliative" drugs are administered in order to hasten death in a manner amounting to euthanasia by act or omission. Secondly, Lorber's rejection of euthanasia is essentially on legal or policy grounds, but not on ethical grounds. He writes that, "... in expert and conscientious hands positive euthanasia could be the most humane way of dealing with such a situation...". But he goes on to say that it should not be legalized because that would be, "a most dangerous weapon in the hands of the state or ignorant or unscrupulous individuals".[304] In a similar vein he writes, "It would be impossible to formulate legislation, however humane are the intentions that could not be abused by the unscrupulous".[305] But from the perspective of the bioethical policy serving as our norm in this thesis, the primary grounds for rejecting active euthanasia should not be considerations of law or policy. The more fundamental and prior reason is the sacredness of life and the conviction that we are its trustees, not its masters. Whether or not those doing the killing are humane or inhumane, scrupulous or not, that prohibition should remain an absolute one.

B. The Freeman "aggressive treatment" policy

A second treatment policy to be examined is that proposed and used by Dr. John Freeman (of the Johns Hopkins Hospital, Baltimore, Maryland). While it is similar to Lorber's policy in some respects, it also differs from Lorber's in some fundamental ways. Both policies are based on the premise and goal that not all newborn infants should be treated and that some should be selected for non-treatment. But whereas Lorber's adverse criteria lead to the non-treatment of very many disabled newborns with spina bifida brought to his institution (about 75 percent), Freeman's criteria lead to a much smaller number who are not treated (about 10 percent).[306] They also differ about how to care for the infants not treated actively, and to some extent about the appropriateness of active euthanasia. As well, Freeman's policy is not as elaborate and detailed as Lorber's, nor has Freeman written about his approach as extensively as has Lorber.[307]

Freeman, like Lorber, bases his selective treatment policy on an essentially consequentialist or utilitarian ethic, one which is essentially personalistic (i.e. seeking the maximum benefit for the infant himself) but to some degree social as well (i.e. seeking the maximum benefit for others). And, also like Lorber, his motivation and goal is predominantly that of minimizing suffering. Freeman however is much more pessimistic than is Lorber about the objectivity of specific physical criteria as infallible predictors of an infant's future quality of life. At the same time he is considerably more optimistic than is Lorber about the expected quality of life of most of the disabled children brought to him.

The first leg of his policy is the arbitrary nature of determinations of impairment and disability. Freeman does give considerable attention to the enterprise of "quantifying" the decision-making process, of attaching numerical values to various impairments, which numerical values would assist physicians in making early decisions for or against active treatment.[308] But he takes considerable care not to exaggerate the importance of efforts to quantify the expected outcomes and benefits of treating or not treating certain impairments by establishing hard and fast adverse physical criteria.[309] Freeman concedes that there is a large quotient of the arbitrary and of opinion when it comes to predicting disability as opposed to impairment. Using the AMA definition of impairment and of disability, he defines impairment as: "an appraisal of the nature and extent of the patient's illness and injury as it affects his personal efficiency in the activities of daily living". As for disability, it is, "the patient's future ability to engage in gainful employment as affected by non-medical factors, such as age, sex, education, economic and social environment and the medical factor".[310]

He goes on to observe:

> Thus, while the neurologic deficit (impairment) present at birth can be predicted with a high degree of certainty, the amount of "disability" attached to that impairment is arbitrarily assigned. Disability is also, however, socially determined. The paraplegic who is excluded from school because he cannot climb stairs is disabled, whereas a school on one floor or the provision of an elevator would minimize the amount of disability. The patient who can walk only with braces but cannot afford them is disabled, but the child's disability can be eliminated by the provision of new braces.311

Freeman then assigns a very optimistic and positive meaning to the medically determinable term "impairment", an understanding which partially explains his policy of treating most spina bifida infants. He uses the term as:

> ... the minimal interference with the activities of daily living brought about by the neurological deficit, with the

> expectation that a society committed to the handicapped will work actively to minimize the disability connected with that given impairment.[312]

He considers two types of impairment as the most important in spina bifida babies - intellectual performance and motor function. When it comes to efforts to attach numerical value to intellectual impairment, he notes that the impairment itself can be assessed by measuring the I.Q., but, "the degree of impairment incurred because of that deficit, the effect on the child's personal efficiency in the activities of daily living, is more arbitrary".[313] Determining the degree of impairment linked to a motor impairment is, writes Freeman, even more arbitrary. There is no question that a person with paraplegia is impaired, but if he is an engineer with a family and good income, the disablement will be partial. If he is a blue collar worker and can't find work then he may be totally disabled. Freeman concludes: "Disability may thus be determined by both intellectual level and motor impairment but is heavily influenced by the forces that society is willing to bring to bear to maximize opportunities and minimize disability. Impairment, however, remains unchanged."[314]

The second leg of his treatment policy involves the conclusions he draws from the fact that many severely disabled infants selected for non-treatment, therefore not treated therapeutically but only given routine care, do not die soon after birth but linger on untreated. In Freeman's view this is the worst possible outcome for the surviving child.[315] That being so, Freeman concludes that of the two choices the physician faces, active euthanasia or aggressive treatment, he would prefer the former. But since active euthanasia is illegal, he adopts aggressive treatment for all but those who are so damaged that they will clearly die soon after birth, as his treatment policy. One expression of that policy and at least one of its supporting legs, is the following:

> Since the editor feels that a slow, natural death over weeks or months is not humane for the child, the family or the staff forced to care for the infant, he is left in the schizophrenic position of advocating either active euthanasia or vigorous treatment. Until active euthanasia for the most severely afflicted children becomes acceptable to society, we must opt for vigorous treatment, to make these children and their families as intact as we are able.316

Before considering in more detail Freeman's views on active euthanasia, we should emphasize the fact that his vigorous treatment policy is not based only on this "what becomes of those selected for non-treatment" argument. That is indeed one leg supporting his policy. But the other is that referred to earlier - the arbitrary nature of predictions about disability and his own more optimistic prediction about disabilities (i.e. expected quality of life), more optimistic compared to Lorber.[317] Freeman brings these various factors together in the following:

> The authors [i.e. Freeman, <u>et al</u>.] are better able to perceive why they and Dr. Lorber can begin from the same consensus for the affected newborn and his family and come to dramatically opposite recommendations. In England, his results (probabilities of outcome) are far worse than those in this country. His society is less able to minimize disability for survivors ... On the other side of the scale, he and the English system give far less disability to the untreated infant waiting to die. Therefore, in quantitative decision-making terms, the utility [i.e. benefit] of treatment of the paraplegic child in England is sufficiently less than the utility of non treatment. Therefore he recommends that they <u>not</u> be treated. The authors find the disability of a prolonged wait for death to be high and find greater utility in those who are treated early. They, therefore, recommend early surgery for most infants with spina bifida.318

Though Freeman does not actually include active euthanasia in his policy in view of its illegality, he does argue that it should be allowed to physicians and should be made legal. In his view the decision to not treat a severely disabled infant is in fact an intention and hope that the child will die quickly, and as such is indistinguishable from shortening its life by active killing. Since "letting nature take its course" involves increased pain and suffering for child and parents, "... should we not then, as physicians, also have the opportunity to alleviate the pain and suffering by accelerating that death?"[319] He then goes on to make his plea that society cease fostering the "fiction" that withholding treatment and terminating life are different, and argues that, "It is time that society began discussing mechanisms by which we can alleviate the pain and suffering for those individuals whom we cannot help".[320]

While Lorber does not think euthanasia should be legalized (because it would be putting a dangerous weapon in the hands of the State), Freeman thinks it should be. But they agree in thinking that it would in principle be the most humane alternative, and neither objects to it on <u>ethical</u> grounds. Freeman in effect argues that it would be the <u>most</u> ethical course, and sees none of the dangers acknowledged by Lorber. But since Freeman's treatment policy itself opts for vigorous treatment, not active euthanasia, we need not spend a great deal of time evaluating his position on euthanasia in the light of our bioethical test prohibiting it. Suffice it to say that the objections raised earlier to Lorber's stance on euthanasia and related matters apply even more emphatically to Freeman.

First of all, our normative Judeo-Christian bioethics contains a strong prohibition against taking the lives of others, no matter what the apparent benefit to that person or others. Secondly, medicine does not have a mandate or duty to erase all suffering and ensure happiness. Third, it is by no means determined to what extent seriously disabled infants experience pain, and if they do, there are drugs available to control the pain without killing the infant.

A last consideration is to determine the weight Freeman gives to social consequences as a criterion in deciding to treat or not to treat. Do factors such as the family's presumed "right" to be free of suffering, the predicted impact on the family and health care providers, the cost of prolonged care, etc. take precedence in Freeman's policy over the right of the disabled infant to life? In our view the answer should be, "no". It is of course true that Freeman frequently refers to the hardship of seriously disabled children on parents and health care providers. But he does not appear to put such considerations ahead of those of the infant, to the point that the right to life of an infant whose medical indications favoured treatment would take second place.[321]

Several aspects of Freeman's position would seem to support this conclusion. First of all, as indicated above, he is well aware of the unpredictable and arbitrary element in attempts to predict disability, including both the impact upon other parties and society, and the future contribution of those parties and society to alleviating disabilities as the infant grows. Secondly, Freeman's policy is generally optimistic and positive about the future contributions to the care of disabled infants. Unlike Lorber's policy, Freeman's is not posited on a pessimistic and unchangeable view of the status quo in that regard, and it does not necessarily let society off the hook in terms of its moral duty to compensate for the needs of our most disadvantaged members. Third, Freeman may not clearly affirm that the right to life of infants with medical indications for treatment should always prevail, but he does at least claim that he resists choosing between what he calls "unacceptable alternatives", adding, "Would I rather have a live child and a broken family, or a dead child and an intact family? I think that we can have both a live child and an intact family."[322] Fourth, Freeman finds that most of his parents do in fact want vigorous treatment for their disabled infants, contrary to what Lorber reports about his parents.[323] Lastly, Freeman makes a strong plea to physicians and others not to project their expectations about a worthwhile quality of life or bearable life onto disabled infants.[324]

C. The Zachary "treat all" policy

The third treatment policy to be considered is the one used and promoted by Dr. R.B. Zachary (of the Children's Hospital, Sheffield). Like his colleague

Dr. Lorber, Zachary has written extensively in explanation and defence of his policy.[325] But unlike Lorber's approach and criteria, Zachary does not base his treatment decisions on expected-quality-of life considerations. His policy could best be characterized as a "treat all"[326] or "medical indications"[327] policy. As such, Zachary's approach is closer to that of Freeman. But a difference between these two policies has to do with one of the most distinctive and explicit features in Zachary's position, namely his insistence that (aggressive) treatment such as surgery need not have only a life-saving purpose.

Zachary begins by identifying three options upon the birth of a baby with a serious spina bifida.[328] In his view they are:

(1) that the baby should be killed; or

(2) that the baby should be "encouraged to die", either by "complete inactivity" (e.g. not feeding) or by "incomplete activity" (e.g. by not treating any illness such as pneumonia, meningitis or any infections by means of antibiotics); or

(3) that the baby should be "encouraged to live".

He rejects the first option, that of direct killing, on religious, philosophical and Hippocratic grounds:

> The ethical principle that the direct and deliberate killing of a human being is wrong is widely accepted on a religious and philosophical basis, and has been the basis of medical practice since the time of Hippocrates, and even earlier. I am talking of medical matters here, not of crime and war.329

Zachary also rejects the second option, insisting not only that these babies be fed, but also (versus Lorber) that their infections should be treated.

> The second alternative has no better justification. To leave a child without food is to kill it as deliberately and directly as if one was cutting its throat. Even the prescribing of antibiotics for infection, such as pneumonia, must now be considered as ordinary care of patients.330

His choice then is the third alternative, that the baby "should be encouraged to live". It is with the goal of giving these children the best chance to live, with their handicaps reduced to a minimum that Zachary chose his management methods and criteria. But before describing and evaluating them, we should determine in greater detail the values or principles upon which his treatment criteria are based.

Careful consideration of his many writings suggests three recurring and related values or principles upon which his treatment policy rests. The first and most fundamental of the three is that the seriously disabled newborn should be given equal consideration to that given to others.

> I believe that our patients, no matter how young or small they are, should receive the same consideration and expert help that would be considered normal in an adult. Just because he is small and because he cannot speak for himself this is no excuse for regarding him as expendable, any more then we would do so on account of race, or creed or colour or poverty ... There are some ways in which modern society cares greatly about those who are less well-off - the poor, the sick, and the handicapped - but it seems that newborn babies are often given less than justice.331

The second of his basic values is a commitment to providing the most development possible for the seriously disabled newborn for whatever period of time that child lives. Whereas Lorber's basic value and motivation, that of "minimizing suffering", was a relatively limited and pessimistic one, Zachary aims higher. He writes for example:

> The surgeon who operates on such a child in the neonatal period has a continuing concern for the fullest development of the child; and I think it is right to emphasize the maximum development of the

> child, rather than the reduction of handicaps to the minimum; for this will influence the whole attitude to the child and his future.332

A third and also recurring principle influencing and woven into his policy is that much of the responsibility for providing the conditions and services needed to promote that development <u>rests on the community</u>. Doing justice to the disabled newborn is a much larger exercise than only devising fair and effective treatment policies in hospitals, and involves not just physicians and other hospital personnel, but the whole community. In particular it is the community's responsibility to provide treatment centres, training for child paraplegics, educational facilities adapted to the special needs of seriously disabled children, (e.g. schools built on one floor, day care centres able to cope with the incontinence of many of these children), and vocational training (with a wide enough scope to develop the wide range of talents of these children). Zachary seems well aware that the provision of all these conditions and services would mean a greater commitment by society to these children, a re-ordering of societal priorities. There is none of Lorber's assumption of a pessimistic and inflexible status quo as regards what the community could and should be doing in this regard. On the contrary, Zachary challenges the community to change, to do more:

> Let us be fair to children born with myelomeningocele. Let us plan their treatment so that their handicap is minimal. Let us develop their minds and bodies so as to compensate for their serious disability, and give them education and vocational training to fit them for a career.[333]

Clearly then, Zachary feels that every child should be treated, though not every child should be operated upon. He insists upon a distinction between "non operative management" and "no treatment", the first being acceptable, but the second unacceptable.[334] Treatment (alone, without operation) is ordinary good baby care, including the provision of antibiotics if needed to fight infections (since to deny such antibiotics is to deny equal treatment), and excluding over-sedating these babies so that they demand little or no food and die in the first weeks (since that is a form of killing).[335]

The criteria he proposes are not therefore criteria for "treatment" (i.e. ordinary good baby care) since that is to be provided to all babies and hence requires no selection criteria. His selection criteria are to guide decisions for or against operations. But Zachary is very emphatic as to the limits and purpose of surgery on these babies, and his position on surgery constitutes a major element of his policy. He insists first of all that it is quite wrong to think that if one operates on a baby with open spina bifida the baby will live, and if you do not it will die. They will not all die spontaneously. Some babies will have a better chance of living if one does *not* operate, and others will die soon even if one operates.

Secondly, he demonstrates that while there is no *necessary* connection between early operation and survival,[336] there are nevertheless advantages to be gained by surgery in some cases, advantages having to do with both survival and function. The primary purpose of surgery is to improve function and prevent further deterioration, not necessarily to save the baby's life. At the same time, improving function and preventing deterioration, as well as aiding development can sometimes prevent later death from complications. That was a conclusion Zachary and Sharrard came to after studying, in 1966, the results of operations done on children between 1955 and 1962, and followed closely up to 1966. They concluded:

> An important point emerged during the analysis of these patients. This was that children who had been treated *without operation* during the early days of life often died many months later from meningitis, or died from complications of the extensive paralysis of the limbs and bladder at some time during the 2nd or 3rd year of life. In those treated by early operation there was a very good chance of further survival if they got through the first 2 months of life. The spine had been treated within the first 4 days of life in 274 infants and by initial conservative management in 252 infants ... we found that however extensive the lesion, early operation always gave a better prognosis *for life* and *better*

> function in the lower limbs in the end. The best results of all were obtained in children in whom the operation was done within the first 24 hours of life. 337

We come now to Zachary's specific criteria for surgical operation. His criteria make it quite clear that he does not at all advocate operating on every baby with serious spina bifida. On the contrary, he quite explicitly excludes a number of categories. But unlike Lorber, the time frame of those criteria is essentially the present not the future, the present medical condition of the baby not the expected quality of life. Two questions in particular are central to his criteria - is the baby's death imminent (if so, an operation is not indicated), and if death is not imminent, is the wound operable (if not, it should not be done). He divides babies with open myelomeningocele into three categories, the first two of which include babies who should not be operated upon:[338]

(1) Those babies judged as likely to die within a few days or a week or so at most. Examples would be those with severe intracranial haemorrhage or some other major life-threatening anomaly. In these cases the issue of whether treatment is ordinary or extraordinary does not even arise, nor questions about long-term disabilities. The child is

dying, and to operate would make no difference as to whether the baby lived or died. An operation in these circumstances would be useless.

(2) Those babies unlikely to die spontaneously and soon, and who have a serious back lesion (e.g. a wide lesion or one producing a severe kyphosis) but who have wounds not suitable for operation. In these cases the chances of primary healing after surgery are small and there would be a risk of wound breakdown. The result of an operation would be worse than no operation. Instead of an operation, such babies should have their wounds dressed and protected from pressure. Many such wounds heal spontaneously.

(3) Those babies who have a good chance of primary wound healing after an operation and the wound is suitable for operation. There are three grades of severity:

Grade 1 - Active movement of the legs is observed after birth. They should be given an urgent operation. Such babies clearly have some muscle power, which could be lost without an operation. Here the purpose is to preserve muscle power in the legs, to provide the best chance possible for maximum mobility and development, whatever the (unpredictable) future is for this child as regards longevity and other factors.

Grade 2 - Certain active muscles such as hip flexors and adductors are observed after birth. Here too, babies in this "intermediate group" have some muscles well worth preserving, and urgent surgery is called for.

Grade 3 - No movement of the baby's legs is observed, and the baby is completely paralysed. For such infants an operation will not have any effect on the baby's leg muscle power. They can be treated either by simple dressings or by a non-urgent operation to remove the swelling (but within 24 to 48 hours to lessen the danger of infection).

Zachary does not pretend that those babies operated upon will be without problems as a result. Whether operated on or not, those survivors who have had a severe myelomeningocele will still remain severely handicapped.[339] But as a result of either good baby care alone or surgery their condition and prospects for development will usually be improved.

As already indicated, Zachary's policy and criteria focus on present medical conditions and the immediate benefit to be achieved for the baby by further intervention, rather than on a prognosis of that infant's future quality of life. But that does not mean that Zachary is unconcerned with the child's future, and in a certain sense, about the child's future quality of life. Not only does he several times refer to "improving the quality of life" of those born with spina bifida,[340] but he seems to use the expression "quality of life" as more or less synonymous with what is clearly the major element of his policy, assisting the "maximum development" of the child. As well, on one occasion he finds support for his policy in one of McCormick's quality of life criteria, namely that babies judged to have the "potential for developing human relationships" should be given all medical assistance possible.[341]

But unlike Lorber, and perhaps even McCormick, the whole thrust of Zachary's values, policy and criteria indicate that future qualities of life are not used so much as <u>tests</u> to be passed before a baby can qualify for treatment now, but as <u>goals</u> to be achieved by treatment, by removing or lessening as much as possible the obstacles threatening those qualities or abilities. Both Spicker and Ramsey seem to have missed this peculiarity in Zachary's use of quality of life when they claim that quality of life considerations and Zachary's "medical indications" policy are in effect mutually exclusive.[342]

In especially two additional respects Zachary differs radically from Lorber and some others in his use of expected quality of life factors. First of all, his policy does not prejudge and in a pessimistic manner the ability of society to provide the services needed to promote and develop the disabled child's qualities. As already indicated above, he does not simply assume the status quo as to the contributions of the community, but challenges it to do more, recognizing that, "... the child is not going to develop in vacuo, he is going to be brought up in a family as part of a community, and his prospects will depend very much on his integration into the life of the family and the possibility of the community supplying any special needs".[343]

Secondly, Zachary's policy gives priority to the rights and interests of the infant, not to the _social_ quality of life factors, the _social_ consequences of treating a child, involving the interests of other parties such as family, health professionals or society. He is of course well aware of the impact on the family of the birth of a seriously handicapped child, both the emotional shock and the financial and other burdens.[344] He is at considerable pains to suggest to those helping the parents sensitive and effective ways of easing the shock and the burden, and argues compellingly for more attention to their needs by the community.[345] But the interests and rights of the infant must come first. He writes in this regard:

> Although we acknowledge and accept these wider effects of our treatment, we have always thought that our primary duty is to the patient, and that the most important decision is to do what is right and best for him.346

Zachary is well aware that other parties may feel that their interests and preferences should come first and that disabled newborn babies are not always treated with equality and justice. He therefore proposes that the physician may sometimes be forced to accept a role of infant advocate:

> Our primary concern must be the well being of the patient - the neonate - so far as it is in our power to achieve it. In his battle at the beginning of life it could well be that his main defence will be in the hands of paediatric and neonatal surgeons.347

A last of our bioethical tests to be applied to Zachary's policy is that of the scope allowed to parental wishes and decision-making. As suggested above in several places (e.g. pp.177-179), parents should have decision-making authority over the care and treatment of their children, but not an absolute authority. Their consent or insistence upon what is in effect medical abuse of their child, or its unjustified death by act or omission, does not relieve the physician of his own moral obligations to his infant patient. As just indicated, the pediatrician may in some cases assume the role of infant advocate, defending for instance the higher right to life of the infant against the lesser interests of the parents.

But the parents do nevertheless have rights in this matter: to be fully informed, and normally to make the treatment decisions about their children as long as the child's life and health is not clearly endangered thereby. Zachary clearly agrees that parents should be fully informed, but he is considerably less clear about their decision-making roles and rights. He does not discuss the place, role and rights of parents at any length in most of his writings, and when he does he appears to <u>assume</u> that if the situation is explained to them with accuracy and sensitivity, they will agree with the physician's assessment and treatment plans.[348] But this may not always in fact be so, and nothing is said or proposed about resolving conflicts should they arise, such as appeals to other physicians, committees or courts for purposes of review and the resolving of differences.

Zachary's silence in this matter constitutes a serious omission in what is in most other respects the medical policy which, of the three considered, most closely reflects the bioethical concerns serving as our norms in this thesis.

3. Conclusions

On the basis of the above analyses of policies in the wide and strict senses, we can now summarize the results of testing physician attitudes and policies against the bioethical norms established in Chapter VI. Our primary interest has been and remains that of determining the influence of theological bioethics on the various attitudes, policies and treatment criteria.

First of all then, to what extent do physicians appear to be committed to the principle of the sanctity of individual life? If that principle means, as we have argued it should, that the right to life of the individual infant may not be subordinated to the lesser rights and interests of other parties, then many physicians do not appear to be committed to the sanctity of life principle. It would be inaccurate to say that they do not give a high priority to the infant's interests and for the highest humanitarian motives of compassion and the desire to minimize suffering. But their respect for the dignity of the life of a disabled infant is more typically expressed in terms of the principle of beneficence, than by a commitment to the sanctity of life principle in its more traditional and rigorous meaning.

The sanctity of life principle fits most comfortably within theological bioethics and a deontological moral system based upon inherent sanctity and inalienable moral rights. The principle of beneficence is particularly at home in philosophical bioethics and a consequentialist or utilitarian moral system, involving essentially a rational calculation of benefits and harms. A commitment to the sanctity of life principle, without necessarily being absolute or vitalistic or admitting of no qualifications, excludes trading off or subordinating the inalienable rights of the infant to the lesser interests of others, and implies a readiness to go "beyond reason" in efforts to protect and enhance that life and those rights. The surveys and personal views section of this chapter (i.e. pp.194ff) leave little doubt that that is not the normative principle and criterion for a large number of physicians. The other points which follow in this summary provide further support for that conclusion.

The absolute prohibition of euthanasia, i.e. killing by act or omission, is a central element of the sanctity of life principle. Because life is a gift and has inherent God-given dignity, we may not take it. The vast majority of physicians surveyed do not appear to practice it, and the three formal medical policies considered do not include it as an option. But the rejection of euthanasia is nevertheless far from unanimous and absolute, nor without much ambiguity. One survey (that by Crane) concludes that there is a strongly held norm in the profession against direct killing. But another survey (that by Shaw, et al.) produced surprisingly large proportions of pediatricians who did not seem certain of their views about euthanasia.

A large proportion (e.g. 32 percent in the Todres survey) of those who claim to be against euthanasia appear to adopt that position not on ethical grounds but because it is against the law, a law they would like to see changed. Duff and Campbell, for instance, are in this category. While two of the formal policies examined, those of Lorber and Freeman, do not promote the killing of newborns, neither reject it on moral grounds. Lorber feels it would be the best solution in many cases, but it is too dangerous a weapon in the hands of the state. Freeman actively campaigns for its legalization and if legalized would practice it. Of those three formal policies, only Zachary rejects killing, without qualification and on sanctity of life grounds. But he insists that many of those institutions using treatment criteria such as Lorber's are knowingly and intentionally killing babies by means of over-sedation and starvation.

The third bioethical test established in Chapter VI has to do with the notion of quality of life, and whether or not treatment policies use that concept in the restricted sense supported by Judeo-Christian bioethics. Used in its "restricted" meaning, the focus is mainly on the consequences of treatment or non-treatment for the newborn's quality of life, and less on the consequences for others. The focus is mainly on the medical indications for or against treatment here and now, its usefulness to the baby and whether or not it might cause that infant excessive hardship, rather than on predictions about long range disability or the availability of services at some future point. Possible burdens to others are important considerations, but more for purposes of post life-saving management than as the decisive factor in deciding whether or not to treat. Quality of life understood in that restricted sense is not in conflict with the sanctity of life principle. That principle imposes a bias in favour of preserving life, so that not to do so is exceptional and requires great caution and specific criteria. But it does not imply a vitalist meaning, an obligation to preserve an infant's life no matter what the resulting burdens will be for that baby.

Neither the surveys of medical attitudes nor the formal policies reveal any significant support for a "vitalist" view in treating the seriously disabled newborns. But very many pediatricians are apparently prepared to allow social quality of life factors (such as predicted burdens on the family or the wishes of the family) to be decisive, even when a newborn is medically salvageable and could benefit from aggressive treatment. That being so it is difficult to conclude that those many physicians are significantly influenced by the major element in the Judeo-Christian stance we have made our norm, namely the bias in favour of life, and the view that the infant's right to a life which could be saved and could be lived without excessive hardship should not have to give way to the (lesser) rights and interests of others.

The surveys and formal policies indicate that many physicians tend to work with a very fixed and personal standard of what is and is not a "minimally acceptable" quality of life. For example Duff and Campbell can affirm with assurance that correcting atresia in a Down's syndrome child is "medicine at its worst", because mental retardation remains.[349] Using as his basic principle and goal that of minimizing suffering, Lorber too appears to be certain as to what is and is not a minimally acceptable quality of life. According to him treatment for a seriously disabled baby is not indicated if for example one can predict institutionalization, or repeated operations, or illegitimacy or inadequate institutions. But other physicians point out the serious inequities implicit in such quality of life standards (e.g. Foss), as well as the large degree of the unknown in predictions about future disability based upon present impairment and about the future availability of needed services (e.g. Zachary).

The often minimalist, pessimistic and subjective views of physicians about the worthwhile quality of life are very likely to some degree an inevitable result of the goal or hope some physicians set for themselves, whether consciously or not. That goal is not just to alleviate or minimize suffering and disability to the extent possible, but to do away with them entirely, to work towards a world without suffering and disability. As well as being obviously utopian and unrealistic such a hope and standard finds no support within Judeo-Christian bioethics or the Hippocratic tradition past and present. But to whatever degree that aim is subscribed to, to that extent chronic and incurable illness tend to be seen as medical failures, and it is easier to conclude that that life would be intolerable for the infant afflicted.

Such expectations and conclusions may explain in part another assumption evident in most of the policies examined - that aggressive treatment or surgery has mainly or only a life-saving goal. Only Zachary makes it a central plank of his policy that the primary goal of surgery should be that of assisting the baby to develop and function as well as possible, to improve or at least preserve its quality of life whether or not the infant is likely to live for a long time and even if its basic impairments are not correctable. Only Zachary, and to a lesser extent Freeman, insist in effect that even when years cannot be added to life, life can be added to the remaining years or months.

As for our fourth bioethical test, that of <u>continuing to care</u> when life-saving is abandoned, the medical surveys, opinions and formal policies examined suggest that this duty receives too little attention, and that there are widely different views as to what should be included in that care. Duff and Campbell for example do not discuss at all the scope and specifics of the duty to care once a decision has been made not to treat an infant actively. When asked in the survey by Shaw, et al., what exactly they would continue to do for an infant from whom life-saving surgery was being withheld, a large proportion of the pediatric respondents provided no answers at all. The same survey indicated a wide divergence in sorts of care which would be provided - most saying they would stop all "supportive treatment", including intravenous feeding and infection fighting, and only a minority indicating they would continue oral feeding on demand. For his part Lorber as well would also exclude intravenous feeding and antibiotics for infections, but does provide sedatives and oral feeding on demand.

Zachary, on the other hand, characterizes the sort of care which combines excessive dosages of sedative with feeding on demand as in effect only a form of killing.[350] In our view he is correct - that approach can hardly be labelled "care" in the ordinary meaning of that word. The sort of care and continuing respect which in our view is involved in "allowing to die" is not simply shifting from doing something to doing nothing. Zachary's own policy does provide for the giving of active care beyond only sedatives.

He provides for both feeding and antibiotics. In his view to treat the seriously disabled (and in some cases dying) newborn differently in this regard from other newborns, by denying them ordinary care, would be to deny their equality. That policy would seem to meet our bioethical test regarding the continuing duty to provide care.

As regards the equal treatment of the mentally and physically disabled newborn, we can only conclude that the Judeo-Christian perspective we are advocating does not seem to have greatly influenced medical attitudes and policies. There is relatively little evidence in these surveys and policies of a commitment by pediatricians to providing equal protection to the most disadvantaged among seriously disabled newborns - those who are mentally as well as physically disabled. For many, mental retardation alone serves as a counter-indication for treatment, whatever the degree of retardation or the extent of physical handicap. The surveys indicate that life-threatening physical problems which are usually corrected in infants who have only physical problems are very often not corrected for infants who are also retarded, even mildly. An example are Down's syndrome babies with atresia or heart defects.

Inasmuch as mental retardation is one of the impairments which cannot be corrected, and because it is assumed (often wrongly) that such children at a later stage will be incapable of performing "useful social roles" or fending for themselves, they become prime targets for selection for non-treatment, either because their affliction is judged to be intolerable for them, and/or because they are assumed to be excessive burdens on family, health care professionals or society. Such is the reasoning in many of the views and policies considered.

But as already indicated, such assumptions and judgments betray a great deal of subjectivity and little awareness of the positive contribution retarded children and adults often make to society, the joy they often bring to others, their own happiness, and their ability to cope by themselves in varying degrees. As well, decisions made in the first days of the lives of such infants on the basis of what services will or will not be available later in life are largely conjectural and provide no challenge to individuals or society to do more to compensate our disadvantaged members.

In some cases the data provided in this chapter suggest a eugenic motivation for the unequal treatment of the mentally retarded, for example the views of Duff and

Campbell. In their view the rights of the mentally disabled are not at all equal to and compatible with those of others, but in competition with them.[351] Clearly not every physician is of that view, a notable exception being Foss who argues compellingly for equal justice.[352]

It would be inaccurate to imply that <u>all</u> treatment policies by physicians discriminate against the mentally retarded infant. Lorber's policy for example contains a form of reverse discrimination. According to his criteria, those with <u>normal</u> intelligence are likely to be selected for non-treatment in the event of serious disabilities, but that should not concern us unduly since in his view the intelligent suffer more since they know their status and what they are missing. But as we indicated earlier, it is surely a lack of respect for the individuality and freedom of each person, and a blatant form of paternalism, to foreclose for these children the chance to make <u>their own</u> decisions and evaluations.[353]

As regards Freeman's policy, he does not appear to discriminate against the mentally retarded infant in his treatment criteria or supporting argumentation. As for Zachary, on this point as on several others, his policy closely reflects the priorities of our Judeo-Christian bioethics. His emphasis on the equality of all infants, his principle that the primary goal of care and treatment should always be to encourage development and preserve function, and his plea for a greater societal contribution towards services and opportunities, all serve as a welcome balance to the discriminatory thrust of the policies of many of his pediatric colleagues.

Another test we established to determine the influence of bioethics on treatment policies is that of the role of <u>parental wishes and parental burdens</u> in decisions to treat or not. As indicated above,[354] there are essentially three models from which to choose in assigning weight to parental wishes in the neonatal context. One is the <u>ownership</u> model, according to which parents own their children and have a right to make all decisions affecting them. This we rejected because parents also have duties and obligations to their children. As well, since an ownership model implies that parents have absolute authority over children it would permit decisions made against their interests.

A second model is that of parents as <u>trustees</u> of their children, according to which they do have decision-making authority, but only up to the point that they do not endanger the infant's rights and best interests, especially those of life and health. In our view this is the most acceptable option from both ethical and legal standpoints. Assuming that a life-saving or function-improving treatment is medically useful and will not impose excessive burdens on the infant, then the lesser rights and interests of parents (or others) should not prevail over the right to life of the infant. In the face of parental refusal of treatment in such a case, we argued that the physician should adopt the role of infant-advocate. In that capacity the physician would first of all attempt to persuade the parents to agree, failing which, if the life itself of the treatable infant is at stake, he could seek court authorization to treat over the parent's objections.

A third model would more or less exclude the parents from involvement in the decision to treat their seriously disabled newborn or not, on the grounds that they would suffer guilt and anxiety if involved, and/or that they are too emotionally involved to make objective choices. This approach implies as well tailoring and limiting the information given to parents in order to protect them from anxiety, and guilt. But we rejected this approach for several reasons. First of all parents do have rights in these matters since they are, after all the parents of the child. Short of threatening the infant's life and health they normally would be the primary decision-makers. Secondly, it is by no means as determined as many physicians imagine that parents always suffer unbearable guilts and anxieties if involved in these decisions, or that they cannot be objective, or that the burdens on them if they keep their child will necessarily be excessive. Thirdly, they have a right to be fully informed of the impairments and prognosis of their disabled newborn, and to be given the time needed to cope with the initial shock and digest the information before making their decision.

Given that parental refusals (and estimates by them or the physician of the burdens on them if their child is saved) can sometimes threaten the infant's right to life, we have argued that decision-making ought to be divided into two more or less distinct parts - one part involves whether or not treatment is indicated, based essentially on medical indications and the best interests of the infant; the other part has to do with subsequent management and care, for instance whether the parents wish to take custody, needed services, choice of institution if parents do not wish to or are unable to take their child home. These latter factors are of course crucially important vis-à-vis long range management of the disabled newborn, but should not be the decisive factors in whether or not the infant's life should be saved.

Applying these factors to the medical views and policies examined in this chapter, it can only be concluded that pediatric decision-making is not greatly influenced by these considerations central to our bioethical norm. Whether consciously or not, many physicians implicitly appear to subscribe to the first model referred to above, that of parental "ownership" of their child. The Todres survey indicates that the great majority of pediatricians questioned would abide by a parental refusal of life-saving treatment for a salvageable infant, i.e., one with Down's syndrome and atresia.[355] While many would attempt to persuade the parents to approve, only a small minority would seek a court order to authorize treatment over parental objections.

Another indication that at least some of the most influential policy-setting pediatricians implicitly lean towards the "parental ownership" model is the position of Duff and Campbell. While they rightly chastize physicians who do not give parents information about their child's condition or involve them in the decision,[356] they tend to make parental wishes decisive no matter what the results for the infant, and in the process they fuse instead of separate the treatment and custody decisions.

As for Lorber's policy, he says very little about parental wishes, except his bold assertion that most parents of spina bifida infants agree with his treatment criteria and the way he applies them. But since he applies them and makes the decision for or against life-saving treatment ideally on the first day, it is doubtful that parents could have absorbed and reflected upon the information sufficiently in the time allowed to be able to characterize their decisions or acquiescence as informed and objective. As well, his own quality of life values and treatment criteria are so definite and specific that it is difficult to picture him being able to shift gears and go along with different values of the parents and a parental disagreement with what he proposes. In fact he nowhere acknowledges that he will treat a disabled newborn selected by him for non-treatment if the parents wish him to do so. In the same vein, his estimates are so pessimistic, rigid and pre-packaged about the future in store for those he disqualifies for treatment according to his criteria, that there seems little incentive for him to consult the parents. As indicated above, parental readiness and ability to provide love and care to these infants can often transform an otherwise bleak future into a positive one for that infant.

One is inclined to conclude that Lorber's policy promotes the third model referred to - one which in effect excludes parental involvement in any significant manner.

As for Freeman's policy, he does not appear to make burdens on the family a decisive factor in treatment decisions, and he does acknowledge that the contribution of families and others can radically alter a disabled newborn's disabilities at later stages in life. Freeman says relatively little in his policy about the role of parents. He does claim that parents generally agree with his aggressive treatment policy . But Lorber made the same claim for his quite opposite early selective treatment policy. Zachary as well is largely silent on the role of the parents, though he does insist that the full situation should be carefully and sensitively explained to the parents. But like Lorber and Freeman he seems to assume that if that is done the parents will agree with the physician's treatment plans.

The only conclusion which seems to follow from this parental agreement with three markedly different approaches is that in the final analysis all three physicians have a great deal more influence on the treatment decisions than do the parents. From our perspective that is regrettable.

Still another of our bioethical tests is whether or not treatment policies are both <u>open and cautious</u>. By a policy which is open we mean one which takes into account the full range of new medical data and complexities, as well as all the relevant principles and values, and is capable of adapting to new information and new challenges. By caution here is meant first of all that both the various forms of data upon which the policies are based, should be more than just assumptions and conjecture, but have been carefully examined and tested, and prove to be accurate. As well, caution imposes a duty on policy-makers to be self-critical, to be aware of the human temptation to enshrine our personal or group values in policies applicable to everyone else, to promote the interests of our own group at the expense of those supposedly being protected.

In varying degrees all three of the formal policies examined tend to omit one or more important considerations and principles and to be too narrow in their scope. For that reason they are not sufficiently open to all the complexities and realities of the problem. Lorber's policy for example is essentially a single principle policy - that of minimizing suffering. But minimizing suffering is only one of several goals and principles which such treatment policies should incorporate. Others are those of preserving the disabled infant's function, and facilitating its development, the more positive principles and goals highlighted by Zachary. And while Lorber is to be praised for exposing the values upon which he constructs his policy - his notion of the minimally acceptable quality of life - it is in the final analysis a highly personal and inflexible viewpoint, in some respects at odds with the views about acceptable quality of life held by many parents of these infants and not open to modification and balancing in their light.

As for Lorber's adverse physical criteria in the form of a single set of symptoms, they seem too fixed and specific to evolve in the light of new and evolving medical knowledge and abilities, as well as new techniques and aids to provide seriously disabled children with more mobility, function and comfort. Applied as rigorously as does Lorber, by his own admission they qualify a number of infants for non-treatment who are only moderately damaged. While they do serve an important purpose, and are particularly useful for the most serious cases, they constitute too narrow a range of considerations to be a sufficient guide to action in all cases.

A further indication of the closed nature of Lorber's policy is his insistence that decisions about life-saving treatment should be made on the first day of a disabled infant's life. A decision that obviously prejudges and precludes the influence of a number of crucially important factors which are not medical in nature and cannot be predicted with any accuracy at birth. All of them could make an enormous difference to a physically and mentally disabled newborn's capacity to cope with its handicaps. Among these non-medical factors are: the physical and moral resilience and the special talents of this particular child (which can only be known for sure later in its life), the care and love its parents are prepared to give it (which in many cases not even the parents are able to predict at the birth of their child), and the social support to be available at later stages in the child's life.

To a much lesser extent some of the same criticisms regarding closed policies are applicable as well to some views and policies of the other physicians considered. While Freeman, like Lorber, also makes the minimizing of suffering his primary motivating principle, his "aggressive treatment" policy does in effect provide most disabled infants with at least the chance to preserve whatever function they might have and to develop further. As well, he is only too aware of the arbitrary and subjective nature of specific physical criteria as indicators of an infant's future quality of life and disability. Furthermore, he adopts a generally optimistic view of the commitment of society to work to minimize the disabilities of these children. But as already indicated above, Freeman's policy gives practically no attention to the influence, if any, which the views and preferences of the parents might have on treatment decisions. Like Lorber he simply states that they generally agree with him. But the policy does not provide guidance as to what to do if they do not agree, by assigning a particular weight or ranking to their role.

While Zachary's policy in most other respects does respond to the variety of complexities, principles and interests inherent in these decisions, it too seems to assume parental agreement and does not in any explicit manner provide for the parental decision-making role or how to handle disagreement between parents and physician.

Turning now to the matter of caution, we conclude that in several respects the views and policies are hasty or inaccurate in their underlying assumptions and data, hence weakening the credibility of the treatment criteria themselves.

First of all, there is a tendency to assume that parents will necessarily suffer intense guilt and anxiety if involved in decision-making to treat or not treat their child, and that they are too shocked to make objective decisions in the interest of their child. Such arguments are used in defence of excluding parents from participating in these decisions and withholding information from them. But while all of these possibilities are sometimes the case, as indicated above[357] some studies suggest that fears about parental guilt, anxiety and subjectivity are exaggerated, and too many uncertainties exist to draw hard and fast conclusions.

Secondly, assumptions about the excessive hardship on families resulting from the survival and taking home of a severely disabled infant, are also to a large degree unpredictable and very difficult to generalize. Several studies and much actual experience suggest that family burdens and disruptions are sometimes exaggerated when compared to the testimony of families who have taken such children home. Yet many of the views and policies examined above opt for non-treatment largely, and sometimes exclusively, on the grounds that the physicians (not necessarily the parents themselves) "foresee" that survival and home custody will be excessively burdensome on the child's parents and family.

Thirdly, these treatment views and policies sometimes assume that seriously disabled infants left untreated at birth will inevitably die soon afterwards.

That seems to be implicit in many of the opinions and practices provided by the surveys we considered. It is certainly the case with Lorber's policy, though not with those of Freeman or Zachary. In Lorber's case we should add the qualification already made earlier, that many of the infants in his care _do_ in fact appear to die soon after the decision not to treat, but that appears to be because they are pushed to die by a combination of heavy sedation and feeding only on demand. But when that practice (equivalent to euthanasia) is not adopted, many infants selected for non-treatment will very often linger on for a prolonged period. Were this fact better realized, more such infants would be treated actively, not necessarily to save their lives, but to lessen their disability and discomfort and improve their lot for whatever period they have left to live.

Another fact about which many of the views and policies appear to be generally uninformed is that of the _legal implications_ of several aspects relating to these treatment decisions. One such issue concerns the legal rights of parents to make decisions concerning their children, and the limits of that right. As already indicated, and as will be further explored in Chapter IX, parents _do_ have the legal right to make health care decisions, one which can only be displaced by exception. That fact casts some legal doubt for example on the practice of those physicians who consistently deny information to parents about the state of their unborn child, or consistently exclude them from a decision-making role. On the other hand, parental authority over their children has its limits and cannot justify risking a salvageable infant's life or health. Not only do parents themselves have no such legal right, but physicians are not relieved of their own legal duties to provide appropriate care if indicated, only because parents might not wish their child to be sustained.

That physicians do have that legal duty does not seem to enter into the calculations of many of the views and policies documented above. Physicians do appear to be well aware that direct killing is illegal, but sometimes not aware of what constitutes killing in the eyes of the law. Killing can be by omission as well as commission. For example, Lorber and many of those questioned in the surveys may in fact be illegally killing infants as opposed to only letting the disease take its course when they over-sedate them and feed them only on demand. Legally, as well as morally that would seem to be "pushing" them to die, not just "allowing" them to die.

A last test to be applied to the medical views and policies considered in this chapter is that of <u>fairness, toleration and interdisciplinarity</u>. Fairness demands that every effort be made to provide equal and just and treatment to all the infants within a given hospital or unit, in other words that the same standards be applied to all. That is of course why guidelines, criteria and policies are needed in the first place - to guard against exposing the rights and interests of the disabled infants (and other parties) to the arbitrariness and subjectivity of those who make or share in treatment decisions.

But the mere devising of a treatment policy and criteria is not sufficient - if the formulation or application of one or another criterion is too loose, or if an essential element such as "who decides" is simply not addressed, it will invite, not preclude subjectivity and arbitrariness. A prevailing fault in this regard is the tendency identified in the medical surveys to allow parental wishes alone to decide the issue as to treatment, even when the child is salvageable and could have a reasonably happy life. Since parents can differ markedly in their abilities and wishes in this regard, if their decision alone is to be decisive then (as is in fact the case now) some salvageable infants will have their lives saved, but others with essentially the same physical conditions and prognosis will not. It is neither just nor fair to place the right to life of infants in such jeopardy.

Another threat to fair life and death decisions for disabled infants, one built into many of the views and policies examined, is the variety and subjectivity of the "acceptable quality of life" views to be found. Compare for example Lorber's value premise that only those infants with "moderate to no disabilities" have lives worth living, with Zachary's view that with proper assistance and encouragement even many seriously disabled can cope and thrive, and that every child should be given an equal chance to survive and thrive if there is any hope at all for that to come to pass. Yet the striking fact is as regards fairness and equality, that both Lorber and Zachary work in the same institution. It is surely unfair to the infants in their care that that institution allows both these quite opposed quality of life notions and the equally opposed criteria which flow from them, to co-exist under one roof. Allowing physicians their freedom of conscience and independence in their practice are of course highly desirable goals. But when their infant patients are thereby denied equality of treatment in matters of life and death, it is time to re-think priorities.

The medical views and policies looked at in this chapter demonstrate a striking absence of <u>inter-disciplinarity</u>. Not only are they formulated exclusively by and for physicians, but in some cases they betray a strong antagonism to other disciplines. As argued above,[358] policies produced by one discipline in isolation from the others risk being incomplete in one respect or another. Medicine contributes the medical/scientific data, the diagnostic and prognostic experience and medical wisdom. Bioethics can contribute skills in the ranking and balancing of the values, rights and principles, and keeps in the forefront the traditional commitment to respect for all human life and the challenge to assist and compensate the disadvantaged. Law identifies the boundaries between socially acceptable and unacceptable activities in this context, and the legal rights, duties and liabilities which follow from that.

But as noted above,[359] Duff and Campbell for example conceive of both law and ethics as doctrinaire and inflexible. Courts in their view simply apply legal doctrine, disregarding family problems and the needs of children. Religion and morals in their view insist on a disease-oriented rather than a person-oriented standard, and sanctity of life rather than quality of life concerns, blindly insisting on treatment in all cases. The law they claim is also an obstacle to good medical practice in that it prohibits euthanasia, something which they imply physicians do but are silent about because they fear the law. The goal they propose is therefore not an interdisciplinary one, but quite the opposite - that medicine keep its distance from both morals and law, and determine its standards of conduct in these matters by itself.

Some other policies as well tend to see law and ethics as having no important or legitimate role and as being more or less obstacles to letting medicine get on with its job. Freeman for example views the illegality of killing as an obstacle to proper medical practice, and argues vociferously for its legalization. He also feels that moralists have nothing useful to contribute to the practical resolution of these problems, and are interested only in matters of "process", not "outcome".[360]

In thereby excluding by omission or outright rejection a positive role for ethics and law in policy-making and policy-implementing, such policies betray considerable ignorance about the real nature of both law and ethics, and the positive contributions each has to make. It seems generally assumed by such pediatricians that the mandate to determine treatment policies is exclusively that of physicians - after all, hospitals and neonatal units are their own world. But such a position overlooks the public (and therefore legal) dimension of these issues, at least when the infant's life or health is at stake, as well as the need to clarify and rank the relevant principles, values, rights, duties and commitments with the help of theological and philosophical bioethics.

Chapter VIII: Bioethical policies

We will turn now to a number of newborn treatment policies proposed by theologians (Fletcher, McCormick and Ramsey) and one formulated by a multi-disciplinary group of which ethicists were only one component. As in the previous chapter, our method and goals here will be to determine as precisely as possible the specifics and supporting arguments of each, how they agree and differ and how each policy measures up to the bioethical tests we have established as our norms in this thesis. The inclusion in this chapter of a rare example of a multi-disciplinary neonatal treatment policy proposal will allow us to draw some conclusions as to whether such an exercise can provide the benefits we have claimed for it. Having already described earlier in this paper the general orientations and frameworks of the bioethics of Fletcher, Ramsey and McCormick, what follows on all three can be relatively brief and will focus exclusively on their views and criteria regarding the treatment of seriously disabled newborns.

A. Fletcher's indicators of humanhood policy

The first task is to determine and evaluate Fletcher's position on the matter of sanctity of life and quality of life. Fletcher clearly belongs to the school of thought which views the sanctity of life principle and quality of life concerns as mutually exclusive, not compatible.[361] He is able to so conclude because he ascribes to the sanctity of life principle an absolute or vitalist meaning - one which makes (mere) biological human life sacrosanct and imposes an absolute duty to preserve life no matter what the prospects, no matter what the damage, no matter whether the interests of the patient are served or not. To that ethic of "rules" or "duties" Fletcher opposes and proposes a quality of life ethic, in the form of an ethic of consequences.[362] According to this approach what makes an act right or wrong is not the degree to which it does or does not conform to a rule, but the degree to which it "serves human values", is an expression of love (or agapé), making the most moral course of action the one which provides a "maximum of desirable consequences". In his view this approach will necessarily involve the forsaking of a rules-based approach to problem solving in favour of a case-by-case approach, focusing upon the particular circumstances of each case (hence "situation" ethics).

In his view then, a sanctity of life approach is absolutist, rule-based, duty-bound, deductive, universalized, an avoidance of moral decision-making because it makes no discrimination between cases, is unconcerned with and insensitive to the condition of or consequences (of treatment) for the patient, and likely to produce inhumane results. The quality of life or consequentialist approach in his mind is the direct opposite of all those things.

Applying to the neonatal context that assumption of the mutual exclusivity of sanctity of life and quality of life, Fletcher writes:

> Pediatric euthanasia is tragic decision making, but to "cop out" of it by universalizing the obligation to preserve the lives of all newborns or children nonselectively, by resolutely adhering to a doctrinnaire moral rule, is simply a whole-hog rejection of the problem itself - a denial maneuver using a taboo to deny that the problem exists at all. .... The norm at stake is, "We ought to do what we can to protect the life of a newborn." If this norm is an absolute moral rule, than any balance of relative values is out of the equation, along with all responsibility of physicians and families as moral agents or "choosers". This follows if the norm has to be adhered to, unweighted by situational variables.363

Referring specifically to sanctity of life and quality of life, Fletcher observes:

> Those who decide what they ought to do by optimizing the values available, as for a spina bifida new-born, have as their guideline the principle of proportionate good, choosing between competing and conflicting

> values. This moral stance contrasts radically with one based on universal negatives (taboos) and blanket imperatives (nonselective duties). One is a decision-making ethic, the other is non-decisional.... Still another way to describe this starting point ... is in terms of a medical ethics based on quality of life as against one based on sanctity of life...364

But to a large extent Fletcher's perceived opposition between sanctity of life and quality of life is a "straw man" argument. After all, as we already noted earlier, hardly any one, whether ethicists or physicians, seriously argues the vitalist or absolute sanctity of life view. Whether some do or not, it is not in our view consistent with traditional or modern Judeo-Christian bioethics.[365] In fact Fletcher almost seems to concede this point himself, despite the elaborate straw man he creates and then at some length demolishes.[366]

As we have argued a number of times earlier in this thesis, an absolute or vitalistic sanctity of life principle is foreign to Judeo-Christian bioethics, and attention to the interests of the patient and the consequences for that patient of treatment or non-treatment is in fact mandated in the final analysis precisely because of respect for each individual life and the quality of that life. In our view the moral system most consistent with

Judeo-Christian bioethics is indeed a deontological or rule based system, in which the sanctity and inalienable moral rights of the patient's life serve as the guiding and limiting principles or rules and normally require that lives be saved and enhanced. But it is a system with qualifications and exceptions. When treatment and life support will for example impose excessive burdens on the newborn, the same sanctity of life principle imposes a duty <u>not</u> to treat. But even here the sanctity of life principle serves a necessary function - it reminds decision-makers that letting a life go is always an exception, and if we are to err it should be on the side of life. As well, it keeps the focus on the rights and interests of the patient. It can accommodate consequentialism, but personalistic consequentialism not social consequentialism. The <u>decisive</u> consideration should be the consequences for the infant patient, not for others.

That being so, Fletcher's picture of a moral system incorporating the sanctity of life as being one of "universal negatives" or "blanket imperatives", one which insists upon treatment in all cases and avoids moral distinctions and decisions, is clearly a construct of his own. There are some serious differences between his policy and the norms serving as our test, but the differences are not at that general level of whether selection for non-treatment is acceptable or not. It is acceptable, but the real issue as always is the criteria and assumptions grounding those decisions, and whether there are limits imposed by principles such as the sanctity of life principle. It is in these matters that we can locate the real differences and the extent to which Fletcher departs from our Judeo-Christian bioethical norms, and it is to those criteria we now turn.

Referring to spina bifida, Fletcher maintains that there are four options as regards the treatment of an afflicted newborn, all of which are acceptable to him:

> (1) Its life can be deliberately ended.
>
> (2) It can be neither cared for nor treated.
>
> (3) It can be cared for only - fed and hydrated but nothing done to save it from its anomalies.
>
> (4) It can be given all-out treatment - meaning not trying piecemeal, stage-by-stage, wait-and-see therapy... Any of these decisions could be right, depending upon the clinical variables.367

As we will indicate below, Fletcher rules out none of these options, including that of killing. But first of all, what are his criteria for deciding whether or not to actively treat a disabled child? In keeping with his general "situation ethics" approach, Fletcher strenuously avoids anything but the most general of statements as to values and criteria. He writes for example that any ends or purposes which validate the standard of "human happiness or well being as the highest good" are just, right and good, or that the best course is one that offers a maximum of desirable consequences in the circumstances of a particular case, or that consequences are good or evil according to whether they "serve human values",[368] or that human rights are imperfect and may be set aside if "human need" requires it.[369] But as a "pure" consequentialist or utilitarian, Fletcher is singularly vague as to what constitutes human happiness or well being, as to what are desirable consequences, as to what kind of human needs justify setting aside rights, and what to do when an infant's rights conflict with another's needs (or interests). The most he does say about the balancing of conflicting values is that the prevention of suffering should come before the preservation of life.[370] But he leaves the reader in the dark as to how much suffering would be enough to justify no longer preserving life.

In effect then Fletcher simply arms physicians with his benediction of the utilitarian principle of maximizing benefits and minimizing harms, the benefits and harms to be determined as physicians are inclined to do already, i.e. on a case-by-case basis. The ethicist has no right to tell the physician what ought to be done - it is up to the moral judgment of the individual physician. He writes in that regard:

> It is certainly not the proper business of ethicists to tell doctors what to do ... The doctor is as much a moral agent as the philosopher or theologian. His moral task is to choose between competing values, and the ethicist's usefulness is only to pursue a differential diagnosis, to help decision makers check out their own judgments and hopefully, avoid leaving something out of their calculations.[371]

Consistent with his utilitarian ethics and the central place he gives to the minimizing of suffering, Fletcher supports the killing of disabled infants from whom it is decided to withhold treatment, on the grounds that it is the compassionate thing to do.[372] That being so, his four treatment options listed above could for all practical purposes be reduced to two - killing or active treatment. Having dispensed with the sanctity of life principle and its implicit prohibition of killing as a disrespect for God-created life, Fletcher has removed what for our Judeo-Christian bioethics is the ultimate deontological shield against carrying consequentialism and compassion that far.

Fletcher also supplements his utilitarian ethics with a series of minimal criteria of humanhood or personal status, according to which one determines not simply whether to treat or not on grounds of maximizing benefits and minimizing harm, but whether or not this infant patient is human, has personal status. If it does not meet the stated criteria, then it has no rights at all, no claims on health care of any kind, and one has no moral duty to support it. It would then be killed with impunity. Those criteria were listed and briefly discussed earlier in this thesis.[373] His twenty criteria for humanhood (later reduced to four) include minimal intelligence, the capacity to relate to others, communication, curiosity and neo-cortical function. According to Fletcher the basic requirement is a minimal level of intelligence.

There are several points worth noting about these criteria as regards the bioethical norms or tests we are applying. First of all, Fletcher is somewhat ambiguous as to the significance of these personhood criteria for the purpose of newborn treatment decisions, and whether disabled newborns (or any newborns for that matter) are persons. On the one hand he writes on one occasion the following:

> If there is any ground at all ethically, as I would contend there is, for allowing or hastening the end of such lives [i.e. defective fetuses, defective newborns, moribund patients], it must be on a qualitative ground, that such human lives are subpersonal. What is critical is personal status, not merely human status.374

But he writes elsewhere, that:

> ... in the case of newborns, these are persons, human beings, so that physicians who decide the end of a malformed infant's life do so on the grounds of a quality of life ethics, not on the grounds that neonatal life is nonpersonal.375

In still another reference to the personhood matter Fletcher writes in effect that it does not matter what one holds about the personhood of neonates:

> The question is not whether a fetus or neonate is a person or not, but whether in some situations, the life of a fetus or neonate may be ended, either one, even though, for whatever reason, they are believed to be persons.

But in our view it does very much matter whether one holds the newborn infant, whether disabled or not, to be persons. If one does not one will obviously be less than strenuous in one's efforts to save it and give it every chance to develop. Fletcher himself is a case in point. He did after all propose and defend his criteria for personhood, and applying them to a Down's syndrome child he concluded, "True guilt arises only from an offence against a person, and a Down's is not a person".[376] Disabled newborns judged to lack the status of persons can be killed without doing wrong since they are not subjects with rights but only objects.[377]

One finds little in Fletcher of what we earlier claimed is central to Judeo-Christian ethics regarding disabled neonates, particularly those also retarded. We refer to the duty to compensate the most disadvantaged members of our society, to offer those with any hope of surviving and coping every opportunity to develop to the fullest extent possible, the challenge and duty to go beyond just reason and logic even at the cost of re-ordering societal priorities. It was as noted a theme highlighted in Zachary's medical policy, but it is largely absent from Fletcher's ethical policy. In fact Fletcher's indicators of humanhood at least implicitly promote the opposite ethic - instead of underlining professional and societal obligations towards the disabled newborn they put the onus on the neonate to prove that it can measure up to our exacting standards. Since it is unlikely in most cases that those qualities or potentialities encompassed by the indicators of personhood can be verified in the earliest period of a newborn's life, they cannot help but put an already handicapped child at still greater risk.

From what Fletcher writes about his values and treatment policy we conclude that he does not insist on the <u>equal treatment of the physically and mentally disabled infant</u>, and on that score as well he is out of step with our normative bioethical tests. Most of his indicators of personal status implicitly or explicitly involve rationality and intelligence. Abilities limited to intelligence are given completely disproportionate attention in his list of indicators at the expense of other abilities and functions, and there is no reference made to the wide latitude in degrees of retardation and brain damage. In his first article on these indicators he proposed a totally arbitrary I.Q. level above which one is a person, and below which one is not.[378] Nor does he refer to the positive achievements many retarded children are capable of and the love they can bring to others.

While Fletcher does focus his quality of life attention on the benefits to the newborn infant, he gives considerable weight, in some respects greater weight, to the <u>social</u> quality of life factors, the impact of treatment on the interests of others. His policy implicitly tips the protective balance to the side of other interests simply by the subjective and discriminatory qualifications for personal status, and the absence of any affirmation of the worth and rights of the disabled infant. As well, he several times endorses directly or indirectly the decisive function in treatment decisions to be played by societal resources and burdens on the family and society.[379]

As for the duty to provide continuing care and comfort, since Fletcher is a promoter of killing infants who were not selected for active treatment, presumably that preferred policy would leave no room for such a duty - those not treated could be killed. Fletcher is however realistic enough to know that killing disabled newborns is not likely to become generally acceptable, at least for some time.[380] Yet despite that touch of realism and the fact that some of these infants not treated actively can live on for some time, he does not argue for any obligation to provide continuing care or indicate what that care should involve.

On the subject of the parental role in decision-making, Fletcher's policy implicitly excludes parents from any significant rights or role. We so conclude on two grounds. First of all his writings are more or less silent on that aspect. Secondly he makes it abundantly clear that decision-making belongs more or less exclusively to the physician. The doctor is referred to as the moral agent in the matter, and it is his moral task to choose between the competing values.[381] He provides us with no views on parental rights to be informed about the condition of their newborn child, nor anything about the limits of parental authority in opting for or against treatment when one or the other course they choose may not be in the infant's best interests. In the light of our bioethical tests his readiness to leave the ethics and decision-making to the physician, and the fact that he does not even address the scope and limits of parental authority, constitute a serious flaw in his policy.

As regards our test of openness and caution, we conclude that Fletcher's policy in many respects is indeed open, but too open. There can be little doubt that a policy which establishes no moral priorities more specific than that of maximizing happiness, which establishes no clear moral limits and leaves all decisions to the moral judgment of the individual physician, will be readily capable of responding flexibly to new and evolving medical data and moral challenges, and can take into account a variety of principles and values. But the kind of response such a policy can provide, and the usefulness of that response, is another matter. Lacking moral positions, rules and a ranking of relevant rights and values, his treatment policy can offer little more in the final analysis than further support for the preference many physicians already have for situationalism.[382] Little wonder that physicians such as Duff and Campbell, seeking as they do to escape ethical and legal "restraints", greatly appreciate the views of Fletcher.

In some other respects his approach is more or less closed to some important considerations. One such is the role of parents in decision-making, how their role relates to that of the physician and the sort of information to which they are entitled.

As for the degree of caution and self-criticism provided for in Fletcher's approach, in some fundamental respects it is in short supply. This is particularly the case with regard to his criteria of personhood. Though they are highly subjective and to a large degree arbitrary and un-tested, they were affirmed in much detail and with assurance. That is particularly so with regard to his emphasis on a specific level of intelligence as a qualification for personhood, especially given the uncertainties and debates about the significance of I.Q.

levels.[383] While there is fairly wide consensus about the justification of at least some of his criteria as quality of life indicators (e.g. neo-cortical function, and the capacity to relate to others), there is no such consensus about their use as indicators of personhood. Such criteria are in other words too subjective, contentious and arbitrary to ground a treatment policy for use in a pluralist context.

As for the degree to which his approach promotes fairness or demonstrates interdisciplinarity, they too are not much in evidence. Given the lack of any rules or ranking of rights, and the moral supremacy of each individual physician, it is difficult to picture how all the infants within a given hospital or unit in which his policy applied could possibly be given equal consideration and needed care whether disabled or not. There is no reason to think such an approach would promote the equal treatment of those with similar problems. It is after all precisely because of the lack of criteria and guidelines at present, the climate of arbitrariness thereby created, and the consequent danger of discrimination, that the formulation of policies and guidelines is so urgent. In this regard Fletcher's approach would seem only to confirm the status quo.

There is no evidence of interdisciplinarity in the formulation or application of Fletcher's policy. As already indicated, his approach is essentially an endorsement of physician decision-making, and even his own discipline of ethics is little more than a bystander since the physician is "as much a moral agent as the philosopher or theologian".[384] That may well be so, and hopefully it is. And it is surely not the job of the ethicist to make moral decisions for others, including physicians. But surely it <u>is</u> the proper role of ethicists to contribute moral guidance in the form of a ranking of principles, rights, duties and values, so that a general moral policy is in place and available to physicians <u>before</u> they exercise their own moral agency faced with a particular case. As for the potential contribution of law, it too is largely ignored. In endorsing euthanasia he pays no attention to its illegality, or the possibility that that position might well reflect the moral views of the largest part of the public. He gives no attention to the legal rights and duties of parents or to the role of courts in resolving (as a last resort) treatment conflicts.

The last of our tests, one reserved for treatment policies by theologians, is that of their <u>participatory</u> contribution and nature. As suggested above,[385] the ideal in our pluralist world is when the theologian plays a participatory role, contributing to a policy along with others (e.g., philosophers, physicians, lawyers, other theologians, etc.), being prepared to respect and learn from their moral insights, but expressing definite convictions and commitments. Such a bioethical policy and contribution need not be formulated in explicitly theological language, but will by definition be based upon Judeo-Christian ethics. Short of denying or overlooking fundamental Judeo-Christian moral principles and rules, the "participatory" theologian and bioethical policy will attempt to seek consensus by proposing criteria acceptable from both humanistic and theological perspectives.

In Fletcher's case there is no danger of anyone accusing him of being the theologian as "prophet" or "preserver". But nor is he being the theologian as participant in the sense just described. Not only does he studiously avoid theological language or reference, but beyond the general admonition to give primacy to love or agapé there is little in his policy which is identifiably theological. In fact, from the perspective of the Judeo-Christian norms and priorities operative in this thesis, Fletcher as we have already concluded is silent or in disagreement. There is no danger at all of Fletcher being thought of as a pushy and moralizing theologian. The real difficulty is to conceive of him as a theologian at all as regards his treatment policy. To a very large extent it is indistinguishable from the policy of a pure utilitarian writing from a humanistic or philosophical perspective.

B. McCormick's quality of life policy

We turn now from the Protestant Joseph Fletcher to the Roman Catholic Richard McCormick. It would be fair to say that vis-à-vis our bioethical tests, McCormick's approach to the treatment of seriously disabled newborns stands in many respects somewhere between that of Joseph Fletcher and Paul Ramsey. Whereas Fletcher rejects the sanctity of life principle and replaces it with quality of life concerns, Ramsey rejects quality of life criteria as incompatible with the sanctity of life. For his part, McCormick argues that quality of life and sanctity of life can be compatible, though he ascribes a somewhat different meaning and orientation to quality of life than does Fletcher.

As already indicated earlier in this thesis, McCormick argues that the Judeo-Christian tradition, "walks a balanced middle path between medical vitalism (that preserves life at any cost) and medical pessimism (that kills when life seems frustrating, burdensome, 'useless')."[386] He insists that the sanctity of life and quality of life approaches are compatible and even inseparable:

> Actually, the two approaches ought not to be set against each other ... Quality-of-life assessments ought to be made within an overall reverence for life, as an extension of one's respect for the sanctity of life. However, there are times when preserving the life of one with no capacity for those aspects of life that we regard as human, is a violation of the sanctity of life itself. Thus, to separate the two approaches and call one <u>sanctity</u> of life, the other <u>quality</u> of life is a false conceptual split....387

He insists upon the sanctity and dignity of the individual person, and strenuously opposes efforts to treat persons functionally. To make that point he cites approvingly Thielicke's position that what gives man his dignity is not his "functional proficiency or his pragmatic utility but "the sacrificial love which God has invested in him".[388] At the same time he rejects the <u>vitalistic</u> sanctity of life approach, one which argues just to be alive is always a success, as if the mere vital processes constitute a good in itself. Against that view he maintains that in the Christian perspective one does not preserve vital and metabolic processes for their own sake no matter what the condition of the patient. While <u>person</u> remains "an incalculable value", it can arise that to continue that person's physical life provides no benefit to that person, and can even do violence to his dignity.[389] But does not the quality of life language imply discrimination in treatment, in that not all lives will deserve equal protection? Not so, writes McCormick. What must be avoided is <u>unjust</u> discrimination, and that is avoided if decisions focus on the benefit to the patient whether or not we describe those benefits in terms of quality of life criteria.[390] His is therefore a deontological normative system, not an absolute one, but a system allowing exceptions based on the consequences.[391] The relevant consequences are those for the infant, not others.

McCormick is well aware of the dangers inherent in promoting a "meaningful life" concept and attempting to determine quality of life criteria. Defending his shift of emphasis from the earlier "ordinary/extraordinary means" approach, he writes:

> The questions, "Is this means too hazardous or difficult to use?", and, "Does this measure only prolong the patient's dying?" while still useful and valid, now often become, "Granted that we can easily save the life, what kind of life are we saving?" This is a quality of life judgment. And we fear it. And certainly we should. But with increased power goes increased responsibility. Since we have the power, we must face the responsibility.[392]

But to limit the most obvious dangers, those of subjectivity, arbitrariness and the substitution of <u>social</u> quality of life considerations for those focused on the <u>infant's</u> condition and benefits, McCormick carefully narrows and defines the meaning and orientation given to quality of life.

First of all, one should place this aspect of his ethics in the wider context of his position on the relationship of individual to community. The individual is an integral part of the community, but must not be totally subordinated to it. The individual cannot be harmed or disadvantaged for the sake of the larger society. That is a fundamental Judeo-Christian standpoint.[393] Applied to his quality of life approach that view can serve as a shield against temptations to make treatment decisions for disabled infants on the basis of consequent benefits to and burdens upon the larger community - e.g., family, parents, health care resources and society generally. Given McCormick's commitment to the sanctity of individual life, it would indeed be "doing harm" to a disabled infant to sacrifice its life or not attempt to provide it with equal care and compensation, in favour of one of those "social" quality of life factors.

Secondly, given McCormick's rejection of assessing and dealing with anyone on the basis of their abilities or functions, as opposed to their God given dignity, his treatment policy and quality of life criteria would have to exclude anything coming under the rubric of "useless to others" or "burden upon others" as a disqualification from life-saving treatment. As he writes himself, a rejection of functionalism as a criterion of value, "... leads to a particular care for the weakest, most voiceless, voteless, defenseless members of society: orphans, the poor, the aged, the mentally and physically sick, the unborn."[394]

Thirdly, McCormick distinguishes carefully between two factors which affect "life's potentiality",[395] on the one hand factors which are "external to the individual", and on the other hand, the "very condition of the individual". Those factors external to the infant, presumably the provision of adequate care, love, health services and opportunities for development, "... we can and must change to maximize individual potential". But quality of life criteria should not include the right to withhold life-saving treatment on the basis of speculation as to the availability of those externals during the course of an infant's life. Nor is the benefit or burden to others the decisive issue, for in McCormick's words, it is necessary, "... to emphasize that these decisions must be made in terms of the child's good, this alone".

What can be decisive, however, and is the legitimate focus of quality of life concerns, is only the condition of the individual. Still more specifically, the question he addresses regarding the infant's condition is, can that condition be so damaged, the prospects so poor, or the post-surgical convalescence so intractably painful and dehumanizing that if treated the mere struggle for survival will "absorb attention and energies to the point where the 'higher, more important good' is simply too difficult to attain?"[396] McCormick concludes, "It is neither inhuman nor un-Christian to say that there comes a point where an individual's condition itself represents the negation of any truly human, that is, relational, potential. When that point is reached, is not the best treatment no treatment?"

Leaving aside for the moment his definition of the "higher, more important good" as being "relational potential", his policy to that point at least would seem to be very much influenced by the bioethical considerations we established earlier as normative. The sanctity of life principle is clearly affirmed, and it serves as the fundamental motivating and limiting principle to his whole approach. But it is not used in its vitalist sense or as if in opposition to quality of life considerations. As well, his policy proposes an appropriately narrow and restricted meaning for quality of life, namely the infant's condition, not the external conditions or benefit and burden to others. He is not unmindful of the influence of external conditions on the child's condition and prospects, but the former should not be the decisive factors in treatment decisions. He insists on the duty to improve those external factors, to cherish and protect the weakest and most vulnerable of these infants, our neighbours, and to ensure that treatment decisions seek primarily the child's benefit, not (primarily) the benefit of others.[397]

But we have a number of reservations about McCormick's use of spiritual ends as the "more important good" which gives value to (physical) life, and the equating of that more important good with the potential for human relationships.

In summary form, McCormick argues the following. The decision to withhold or stop life-saving treatment can be made in some cases on grounds that the means necessary are extraordinary (or "unreasonable"),[398] that is, because it will entail excessive pain and hardship. In some other cases treatment can be withheld or stopped on quality of life grounds, that is, because mere physical or metabolic life is not a value in itself, but only insofar as the higher values, i.e., love of God and neighbour, are made possible.[399] Applied to seriously disabled newborns, if the potentiality for human relations is either completely lacking or undeveloped or completely subordinated to efforts for survival, then treatment is not obligatory because that life has already achieved its potential.

Few would quarrel with the affirmation that capacity for human relations is an important human function, perhaps even the most important. But to make this single value, capacity or function the criterion of whether there is or is not a duty to support some lives may well be claiming too much for it.

First of all, relational potential is inescapably vague and relative. McCormick to some extent seems to acknowledge this himself. He notes that it is not a detailed rule, or subject to mathematical precision or sufficient in itself without further detail. It is up to physicians "to provide some more concrete categories or presumptive biological symptoms for this human judgment".[400] But since such categories or biological symptoms are intended to confirm the presence or absence of some degree of relational capacity, they would beg the question as to what degree of relational capacity should require us to support an infant's life.

The example McCormick himself provides of how biological symptoms could give us something more concrete, in fact only illustrate the problem - he argues that because an anencephalic infant has no relational potential it need not be treated, whereas a Down's infant does have such potential and should be treated. While we agree with his conclusion, "relational potential" may be only one of the grounds for treating the Down's child and not the anencephalic. Surely in the case of the anencephalic infant (and many others) a more obvious and substantial reason is that that child will not survive long with or without treatment. And what of all the degrees of relational potential between the anencephalic and the Down's child, and even <u>within</u> the category of Down's syndrome infants?

Secondly, the achievement of human relationships depends not only on the inherent capacity to relate of just one party to the relationship. How can one determine relational potential without measuring as well the encouragement and incentive to relate which will hopefully be provided to the disabled infant during the course of its life? Since that cannot be known with any accuracy at the start of life, using that criterion as the decisive factor for or against treatment may not be justified. Obviously the relational stimulus and training which others can provide to a disabled infant is not a relevant factor in the case of anencephalic newborns, but it can be for those less damaged.

Thirdly, because the relational potential criterion is necessarily vague and relative, it cannot help but lack equality in its application, and is therefore potentially unjust.[401] It is simply a fact that not every person, disabled or not, infant or not, has the same level of capacity to relate. Therefore to require a specific level for treatment purposes is likely to be unjust.

A further difficulty is the impression created that expected accomplishments or achievements (i.e. relational abilities) are to be the standard for qualifying for life-saving treatment, which suggests exactly the sort of functionalism McCormick himself rejects as noted above. He himself insists that what merits respect and protection in humans is not what they <u>do</u> or accomplish, but what they <u>are</u> - beings created, cherished and loved by God. But in proposing the relational abilities criterion, he appears to be in violation of his own commitment to respecting life for what it <u>is</u>.[402]

McCormick's treatment approach is by no means a comprehensive policy capable of standing on its own and by itself in a hospital or neonatal unit, nor does it pretend to be. His concern is to provide a justification, faithful to Judeo-Christian theology, for a relatively narrow notion of quality of life to be the decisive factor in some decisions not to treat. "Relatively" narrow that is when compared for instance to Fletcher's views, but not narrow enough in our view for reasons indicated above. But he is quite aware that his general principles need supplementing by more concrete categories and biological symptoms, and by more reflection about what is a "reasonable" option vis-à-vis treatment in cases of seriously disabled newborns given a variety of conditions and prospects. Given all that, we do not find in McCormick's position enough specifics and detail to know for certain how his approach measures up to all our remaining bioethical tests. But we can at least draw some tentative conclusions by "reading between the lines" of what he _does_ say.

Though McCormick does not explicitly address the morality or immorality of _euthanasia_ or killing, its rejection appears to be implicit in his strong insistence upon the sanctity of life and its God-given and God-cherished nature. As well, his explicit concern throughout is to justify in some circumstances the withholding of life-sustaining treatment, not killing that newborn by act or omission. The same point would seem to apply to the continuing duty to provide care and comfort in the event that therapeutic treatment is deemed to be useless. He does not explicitly deal with the point made so strongly by Ramsey, that the duty to care continues even when efforts to cure or save life cease, or the additional point insisted upon by Zachary, that caring treatment can be called for not just in order to save a life but also to preserve function for whatever period that infant lives. Though he does not explicitly address these points, his commitment to acting always in the infant's best interests, and to the protection of the weak and most vulnerable implies continuing care and concern for the infant whether treated therapeutically or not.

As regards another of our tests, that of protecting and treating equally or fairly the mentally and physically disabled, the general principles and orientation of his policy - e.g. the rejection of unjust discrimination, the centrality of benefit to the patient, and the duty to protect and cherish the most vulnerable of our neighbours - would seem to ensure that the mentally disabled infant would be safe from discrimination under his policy. Unfortunately, however, it is hard to see how his quality of life criterion of relational potentiality would not put the mentally disabled infant at greater risk than the one who is only physically disabled. The capacity to establish and maintain human relationships is, after all, largely (though not exclusively) dependant upon intellectual and emotional abilities, both of which the retarded infant will be in short supply of to one degree or another.

McCormick would no doubt reply that, yes, there will of course be discrimination, but not unjust discrimination given the differences in capacities and potentialities, and the focus on the infant's benefit. That may of course be so when the newborn is accurately diagnosed to be without any capacity to relate (e.g. the anencephalic infant). In such cases it may well be to the infant's benefit not to initiate life-saving treatment (which may not even be possible). That degree of retardation is likely to be accompanied by other very serious physical problems and impairments, and the infant will either have no interests at all, or to treat it therapeutically would be to inflict or perpetuate excessive hardship. But for relational incapacity less than total, it is difficult, if not impossible, to establish the point at which it is truly beneficial, hence not discriminatory, to allow it to die.

After all, how much relational capacity, and at what level of mentation (as opposed to less intellectual and more instinctual levels) is to be considered enough to indicate human potentiality and hence treatment? Can that question really be answered with enough consensus and precision to formulate concrete biological symptoms and criteria to confirm its presence or absence? One doubts that this can be done without much subjectivity and arbitrariness. If that is so, this criterion of relational potentiality is likely to further encourage that tendency noted earlier, to apply far less rigorous and careful standards to treatment decisions for the mentally retarded compared to those who are only physically handicapped. As well, there would inevitably be unfairness within the mentally retarded category itself.[402a]

With regard to parental decision-making authority, McCormick's policy does not establish any specific guidelines, nor does he even discuss the issue. However, the general principles and goals of his policy, especially those of benefitting and protecting the infant and avoiding unjust discrimination, would seem to rule out allowing parental decisions prejudicial to the infant's welfare to be decisive in opting for or against treatment. That this is indeed McCormick's view is further confirmed by his disapproval of the outcome in the famous "John Hopkins case", in which parents refused permission to correct the intestinal blockage in their Down's syndrome child, the doctors acquiesced and the baby died by starvation.[403] As regards the rights of parents, that is, those of normally being the decision-makers, and of being informed about their child's condition and the treatment options, McCormick affirms that in the majority of cases, including those which fall into the gray area, "... individual decisions will remain the anguishing onuses of parents in consultation with physicians".[404]

Given both the generality of McCormick's policy, and the vagueness of his relational potential criterion, his approach is certainly not a closed one. It is very definitely open to new medical data and challenges. The very fact that it needs supplementing (as McCormick acknowledges) by more specific categories and medical criteria, underlines its open and potentially evolving nature. In some respects that is a very definite plus factor, especially when compared for instance to the excessively detailed and "frozen" criteria used by Lorber. But, as already implied above, in some respects his approach is not open enough, that is, open to all the ethical priorities and principles. In view of his relational capacities standard, one of these threatened values is that of fairness. At the same time his policy betrays some lack of caution, in that capacity to have human relationships is altogether too contentious, vague and variable to play the definitive normative role in our pluralist context given to it by McCormick for some cases.

Interdisciplinarity does not appear to be a major feature of McCormick's treatment policy, though he does leave more than ample room for contribution by physicians to such a policy. It seems fairly clear from what he writes that in his view the role of ethics and ethicists in policy making is that of establishing on solid moral grounds the general ethical principles, priorities and criteria in the form of guidelines which should underlie the more specific medical categories or biological symptoms serving as the operative criteria. But these latter criteria are for physicians, not ethicists to provide. To this point we agree fully, though ideally physicians will also have important ethical insights to contribute to the general ethical principles and priorities.

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But where his approach is somewhat deficient is the implication that once the ethicists have established those general principles and values, they then back off, and leave physicians a free hand in efforts to make the specific medical/biological criteria consistent with the general principles and values. But in our view that would be an abdication of one aspect of the ethicist's role in contributing to policies. It is of course true that the medical experience and wisdom of physicians makes them uniquely equipped to propose the specific medical conditions and criteria which could be decisive for or against treatment. But the ethicist should retain some role in judging their <u>morality</u>. This would especially be the case when the <u>general</u> ethical quality of life standard is as vague and open-ended as that of "relational capacity". It invites subjectivity and arbitrariness in the medical/biological symptoms and hence requires ethical review and evaluation of those symptoms.

A point made above (p.182b) should be recalled here, namely that just because a newborn treatment policy is to apply in a hospital or neonatal unit does not imply that physicians alone should formulate it. These policies will inevitably have large ethical and public policy quotients. Given that public policy dimension, the law too has an important role to play. McCormick, however, does not refer at all to the public policy dimension or the role of law.

Whatever our judgment of some aspects of McCormick's policy, it is undoubtedly participatory in nature. He is on the one hand clear and emphatic about his points of view and convictions, but at the same time he conceives his approach as only a contribution towards a policy requiring the insights and experience of others. He goes to great pains to assure us that his approach is not totally original and personal, but shares a great deal with the views of many other bioethicists, and he is prepared to debate with and take seriously those who disagree with him on one or more points.[405]

C. Ramsey's medical indicators policy

The two most distinguishing features of Ramsey's treatment policy are first of all his choice of a medical indicators approach rather than the ordinary/ extraordinary means or the quality of life approaches, and secondly, his insistence that even when curative treatment ceases (because the patient is dying regardless) there is a continuing obligation to care. Most of our description and evaluation of his policy in the light of our bioethical tests can be related to these two legs of his position.[406]

Underlying both of them and binding them together is Ramsey's strong commitment, already noted earlier in this thesis (pages 88-95), to the sanctity of individual life:

> 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...407

Ramsey's first concern, the one evident in his choice of a medical indicators policy, is to remain focused on the objective condition of the patient rather than to the wishes and subjective preference of various parties involved. That was, he acknowledges, a strong point about the ordinary/extraordinary means approach - it tended to focus on the patient's condition and the available medical remedies, and whether a patient's refusal of treatment amounted to "choosing death" (i.e. rejecting an ordinary treatment) or rejecting an excessive hardship (i.e. excessive costs, too long a journey, repugnance of disfigurement, unwillingness to leave home). But he feels that a medical indications policy is preferable. It too focuses on the objective condition of the patient, but avoids some of the ambiguities of the means approach (which in his view implies a "customary medical practice standard"). He refers to the terms "ordinary" and "extraordinary" used as a treatment guide, as "cumbersome, opaque and unilluminating."408

But his main reason for rejecting the means approach is that that approach was meant to be applied by patients who could make their own choices, and not those already dying, and by those whose lives could be meaningfully prolonged by heroic means. He writes:

> Today we are beginning to think it may be right to do unto others (i.e. refuse treatment for voiceless patients, whether dying or not) as conscious competent patients in former times could do for themselves (refuse extraordinary or heroic means and some standard ones as well). Thus the original meaning of the ordinary/extraordinary distinction is applied to cases for which it was never intended. That leads straight to quality-of-expected life judgments in the case of the desperately ill or "incurables" who are voiceless. We are beginning to think of them as dying.409

He therefore opts for abandoning the "means" approach in favour of a medical indications approach. That policy can be simply described. It first of all assumes and includes making a clear distinction between the dying and those not dying. For those who are dying and will die despite treatment, attempts to cure or save life are no longer medically indicated. Instead, we must provide them with care and comfort while they die. For those not dying, this policy insists that they <u>should</u> be treated (not "allowed to die" since they are not dying). The question in their cases not being whether or not to treat, but choosing between treatments, choosing the particular treatment which is medically indicated in view of the patient's condition. In Ramsey's view such an approach is, "... a more subtle and more patient-oriented modulation of what was meant by ordinary/extraordinary...".[410] Yet it remains objective as well as patient-oriented because, "... a comparison of treatments, or of treatment with no further curative treatments, is objectively relative to the patient's present condition - not to some notion of standard medical care in a physician's mind."[411]

Ramsey is particularly emphatic and absolute in his rejection of quality of life considerations, and in particular in his disagreement with McCormick's approach and his relational capacity criterion. He accuses him of shifting the ordinary/extraordinary means approach away from the conscious non-dying patient and erroneously and dangerously applying it to non-dying patients incapable of sharing in that decision. It is applied: "to a non-dying patient's developmental human potential or to a geriatric patient's lost further potential ... McCormick takes the step from discussing whether treatments are in some measure beneficial to patients to discussing whether patient's lives are beneficial to them."[412]

To examine and evaluate Ramsey's position regarding quality of life, and to determine the implications of his medical indications policy, we move now from his general framework to the specific context of the severely disabled infant.

Applied in this context, Ramsey wholeheartedly approves of Dr. Zachary's treatment policy which was described and evaluated earlier in this thesis (pp.284-298). In his view Zachary's tests for no treatment differ substantially from McCormick's and comprise an excellent example of a medical indications policy since he asks only whether the child's death is impending or whether the wound is inoperable.[413]

Ramsey concludes about disabled newborns, that the same dangerous fusing of two quite different categories takes place as noted with adult patients - the dying and the non-dying patient. Many handicapped newborns are born dying and may well be beyond curative treatment. In these cases the grounds for not treating are that it cannot help or might make them worse. But many who are "benignly neglected", not being treated and "allowed to die" are not in fact dying. Instead, writes Ramsey, they are being pushed to die (e.g. as Lorber appears to be doing by over-sedation and starvation). The non-dying should be treated actively, the only question being the choice of treatment depending on the child's condition.

He takes serious issue not only with Lorber on not distinguishing between the dying and non-dying, but also with Duff and Campbell who reported the deaths of those with severe impairments but not dying as having been "permitted to die", no doubt, adds Ramsey, because they were not treated.[414] The standard for letting a disabled newborn child die, insists Ramsey, must be the same as that applied to a normal child. A normal child with a bowel obstruction would be operated upon to remove it - the same should be done for a Down's syndrome child with duodenal atresia.

As far as Ramsey is concerned the "benign neglect" of non-dying defective infants is simply a form of involuntary euthanasia, both in the eyes of morality and the law, for:

> ... when care is not even attempted in the case of defective non-dying infants, there is no morally significant distinction between action and abstention. Morally, what in this case is not done is the same as doing. The benign neglect of defective infants - who are not dying, who cannot themselves refuse treatment, who are most in need of human help - is the same as directly dispatching them in voluntary euthanasia.[415]

He argues about the defective infant situation as he did about adults, that the continuing use of "ordinary" and "extraordinary" beyond the context of the conscious patient is one of the pressures pushing us towards involuntary euthanasia. As well, he fears that active involuntary euthanasia is thereby made more attractive and likely:

> It happens to be a good moral argument (granting the premise, which I do not) to ask, if we may withhold medically indicated treatment (or only give treatments called for by quality of life expectations), why may we not directly kill instead? Nonvoluntary euthanasia and substituted judgments about fortunate death will be the terms that ease our passage to direct killing.[416]

Ramsey emphatically rejects the attempts by Fletcher and others to find "indicators of personhood" as being an attempt to play God but not the way God plays God, for, "... there is no indication at all that God is a rationalist whose care is a function of indicators of our personhood, or of our achievement within those capacities. He makes his rain to fall upon the just and the unjust alike, and his sun to rise on the abnormal as well as the normal."[417] Even to seek such indicators is misguided he claims because, "... it would launch neonatal medicine upon a trackless ocean of uncertainty, directly into arbitrary winds".[418]

What is legitimate he maintains is a medical indications policy, one requiring a:

> ... choice among beneficial treatments and a simple refusal to use medically nonbeneficial measures. The question to be asked concerning nondying patients incapable of consent is, what will help, what will ease? To continue discussion of these crucial issues under the alternative "to save or let die" forces an ethicist or a physician to move from consultation about conditions of life that are beneficial to the possessor thereof."419

Before moving on to consider Ramsey's application of the continuing obligation to care to the disabled infant context, we should comment on the significance and implications of his medical indicators policy. The triple-barrelled question to be answered is whether a quality of life approach really is necessarily as threatening to the sanctity of life as Ramsey maintains, whether a medical indications policy is, as he insists, a marked improvement upon the "means" approach, and whether a medical indications policy really can be totally insulated from quality of life considerations as he claims. We are not persuaded that any of these questions should be answered with a clear affirmative.

As we have indicated several times earlier in this study, the Judeo-Christian insistence upon the sanctity of individual life does indeed oblige us to incorporate as essential factors in treatment policies elements such as fairness, justice and objectivity. Excessive subjectivity and arbitrariness are clearly inimical to respect for individual dignity. We therefore agree with Ramsey that the standard for letting a disabled newborn child die should be the same as that applied to a normal child, or as Zachary put it, that just because the newborn is little, helpless and unable to speak is no excuse for not extending the same consideration and expert help considered normal for an adult.[420] We also agree with Ramsey, for reasons already indicated, that McCormick's "relational capacity" may well be too personal, subjective and open to arbitrary interpretations to serve as the single all-encompassing quality of life criterion. The same is true for Fletcher's "indicators of personhood". And, finally, we agree that non-dying disabled infants should normally be treated and have their lives saved and that the decisive consideration should be their medical condition.

But that said, we do not agree that all quality of life or expected-quality-of-life factors are always out-of-order for the non-dying, and always incompatible with the sanctity of life principle. Relational potential and indicators of humanhood may well be too vague and achievement oriented. But surely it depends upon what qualities or conditions are at issue, whether subjectivity and abuses can be minimized, and whether patient benefit is the primary concern.

First of all, Ramsey regrets that the ordinary/extraordinary means approach is often applied beyond its original context, that of the non-dying and competent adult. But there is no inherent reason why the "excessively burdensome" criterion, legitimately used by competent adults to refuse available life-saving treatment according to the means approach, cannot in some cases be applied by physicians and families to disabled non-dying infants. In effect that criterion focuses on the qualities of life which would be affected if treatment were undertaken - e.g. leaving home, disfigurement resulting from the operation, the loss of an important means of communication such as speech, etc. There seems no reason to conclude, as does Ramsey at least by implication, that families and physicians cannot make a reasonable judgment as to whether the burdens resulting from an operation on a non-dying seriously disabled child might impose an excessive burden on that infant, thereby making the treatment "extraordinary".

Of course there are dangers, and absolute objectivity and certainty cannot be guaranteed, but no approach, including a medical indications one can exclude all subjectivity or the need for medical judgment in the diagnosis and prognosis. To deny the availability of this inherently quality of life approach to the non-dying disabled infant could be construed as a form of discrimination and unequal treatment. To allow it is to find Ramsey's medical indicators policy deficient in the way he applies it to the non-dying disabled infant - rather than just involving a "comparison of (curative) treatments", it should include as well the possibility of no (curative) treatment at all.

Secondly, as noted above Ramsey argues that quality-of-expected-life concerns force ethicists and physicians to move from considering, "beneficial and non-beneficial treatments" (alone), to then considering "conditions of life that are beneficial", and finally, "to the possessor thereof". But how can one make an informed judgment about whether a treatment is or is not "beneficial" without making a prior prognosis and judgment about the "conditions [i.e. qualities] of life" which will be affected, improved or limited by the treatments under consideration, and whether one (or all) of the available treatments could reasonably be construed as likely to make things worse by imposing an excessive burden? To propose the sort of wall Ramsey does between (strictly) medical indications and the conditions resulting, verges on a vitalist policy, and/or would seem to limit treatment decisions only to present medical conditions to the exclusion of prognoses about longer-range results for the whole patient.

It would seem to us then that a policy based upon a choice between medically indicated and non-indicated treatment cannot reasonably exclude weighing some quality of life implications and including them in the calculation as to what treatment is or is not indicated. In the final analysis real disagreement would seem to be more about what patient conditions should count as legitimate quality of life considerations.

It is by no means clear that Ramsey's medical indications policy is a marked improvement on the ordinary/extraordinary means approach. The latter may well be ambiguous, but Ramsey is incorrect to imply that the prevailing interpretation of "ordinary" is that of "usual" and that the approach focused exclusively on a classification of the treatments themselves to the exclusion of the particular circumstances and conditions of patients. Most physicians (and ethicists) are sophisticated enough to have been well aware that what is ordinary or extraordinary depends in the final analysis on the patient's condition, circumstances and prognosis. As indicated above, that this is indeed the prevailing view is confirmed by the surveys of physicians.[421]

No policy formulation alone, whether "ordinary/ extraordinary", "quality of life" or "medical indications", provides without further detail the objective features which will make a treatment "ordinary", or "indicated". Ramsey does not tell us in the formula itself what it is that will make a treatment "indicated", nor are the notions of "curative" treatment or "dying" patient readily transparent. As McCormick for example has pointed out, the notion of "curative" has many levels - it could mean for example simply staving off death, or it could mean full recovery, or various stages in between.[422] Whatever the particular terminology of the policy label then, including Ramsey's, they can all be somewhat "cumbersome, opaque and unilluminating" without further clarification and explanation.

Nor are the "means" policy, the "quality of life" policy or the "medical indicators" policy necessarily free of potential abuses such as excessive subjectivity, discrimination or arbitrariness. In each case it is not the terminology or label which counts, but the meaning and application given to the policy and its terms. It is highly doubtful that anyone can support a claim that the "means" approach protects life better than the quality of life approach, or vice-versa, or that Ramsey can support his claim that a medical indicators policy clearly protects newborn life better than the others. It depends mainly on where the lines are drawn in each case and not on the language alone.[423]

We turn now to the second leg of Ramsey's policy, his insistence on the continuing obligation to care for the dying. His general position in that regard was already described earlier in the thesis (p.91). Here the focus is on its application to the context of the newborn infant, and specifically on a point dealt with at some length by Ramsey - is it ever morally permissible in the case of the dying infant to shift from caring to killing? In other words, is <u>active euthanasia</u> absolutely prohibited in his policy, or are there exceptions?

By way of preamble we should note that Ramsey offers no examples at all of exceptions to his principle that equally vigorous treatment should be given to (non-dying) disabled newborns as to the non-disabled. He does consider the case of the anencephalic newborn,[424] a case where McCormick feels it is justified not to treat. But Ramsey's position is that treatment should not even be at issue in this case, because such infants are already born dying and therefore the morality of letting die clearly applies. He goes on to argue (persuasively, in our view) that in fact such an infant (though generically human) is not in reality born alive since it is lacking a brain,[425] and therefore does not even "enter the human community" or make a claim to our care and protection any more than does a brain dead adult on a heart-lung machine. That being so, we are not only justified in withholding life-prolonging treatment from such infants, but if they persisted in living in that condition (which they do not), we should be willing to "kill" them. As he goes on to note, however, to speak of "killing" them is a misnomer since one can commit homicide only on those born alive.

But can there ever be exceptions to his moral rule, (one we have endorsed and adopted as one of our bioethical tests) that we should never abandon the care of the dying?

Earlier in this thesis (pp.93-95) we outlined Ramsey's general and tentative response (provided in his 1970 book The Patient as Person), namely that there could perhaps be two exceptions - one being when the dying person is completely and irreversibly beyond our reach and care, when it has become a matter of indifference to that person whether or not we continue to provide care; the second example being those involved in a prolonged dying process who are in intractable pain. For both cases Ramsey acknowledged that by exception hastening their death by active euthanasia would be morally permissible.

He returned to those exceptions some years later (in his 1975 Bampton lectures, revised and published in his 1978 book Ethics at the Edges of Life) to apply them to disabled infants and to re-evaluate them in the light of earlier criticisms. Ramsey first of all proposes an example of a birth defect of a terminally ill infant which is so severe that in his view it puts him beyond human care and may abolish "the moral distinction between always continuing to care and direct dispatch".[426] That example is the genetic defect referred to as Lesch-Nyan. There is, apparently, no therapy for it and its victims suffer uncontrollable spasms and mental retardation. When their teeth begin to appear they do great damage to themselves by biting, gnawing through and self-mutilating any part of their own bodies they can reach. They are in Ramsey's view beyond care.

But in the light of a number of criticisms, Ramsey provides a number of clarifications, and finally as well, almost a retraction as to the existence of exceptions to the moral prohibition against killing. He first of all insists that only <u>total</u> accessibility could justify the end to the obligation to provide care, which would not threaten the principle that there is a continuing obligation to provide it, but simply acknowledges there is a point beyond which it cannot go. Secondly, he makes it clear that these exceptions are just that - not proposed as a "rule of general practice", but only providing that in exceptional and individual instances one may not be morally culpable for contravening the general rule. His exceptions in other words were not meant to be turned into the rule of general practice some others have made of it Thirdly, he insists that his only interest was in "whether there ever comes a time when the care of a human agent ... no longer reaches the subject cared for...",[427] and never that:

> ... one should base moral judgments in any degree upon an evaluation of the patient subject as such. There was not the slightest suggestion that one should decide <u>first</u> whether the patient-subjects are so overwhelmed by their struggle for existence that they have lost effective capacity for meaningful relationship. No quality-of-life judgments were given entrance; only uselessness of agent care was suggested.428

It would appear that in this last clarification Ramsey in his eagerness to resist any taint of quality of life thinking, is making altogether too fine a distinction, one which seems to defy logic and common sense. Though denying vehemently any quality of life intrusion, he in effect concurrently takes full advantage of an obviously quality of life argument while pretending it is something else. It surely is straining logic to the utmost to insist that patient care and patient condition can be divorced in the manner he does, or that the overwhelmed condition of the disabled infant is not the ultimate reason why human care can go no further. We do not ourselves agree that these exceptions should permit killing, even by exception (for the reasons given below), but he has in our view made a convincing <u>quality of life</u> argument for an instance in which care and accessibility may indeed have their limits.

After making the above clarifications about his earlier position, Ramsey then proceeds to almost but not quite retract his original view on the legitimacy of killing a dying patient who is "beyond care". His moral reason for prohibiting direct killing or hastening death was the duty to always care for the dying. But when a patient becomes inaccessible to care and that care comes to an end, then (he had argued) the distinction between directly killing and allowing to die becomes "a matter of indifference".

But a number of objections were made to that conclusion, three of the most serious were from Maguire, McCormick and Jonas. Maguire argued that the exceptions were not as carefully circumscribed as Ramsey claimed, since neither physicians nor ethicists are at all sure when the dying patient enters into "impenetrable solitude".[429] McCormick made a similar point, but added as well that the duties of caring are not necessarily limited by the limits of "care's communications" but the self-consciousness of the patient, a function which may well persist long after ability to communicate is lost.[430] As for Jonas, he made an important distinction between on the one hand ceasing efforts to delay death, and on the other hand when to start doing violence to the body. For the first purpose we only need to know that the coma is irreversible, but for the second we need to know the borderline between life and death with absolute certainty. Since we don't know that, nothing short of the "maximal definition" of death will do. Jonas concludes that any sustaining artifice on an irreversibly comatose patient can be turned off, but, "let him die all the way. Do not, instead, arrest the process...".[431]

Ramsey does not quite retract his earlier exceptions in the face of these criticisms, but he does admit they are indeed serious moral objections and promote an ethics of respecting life and continuing care right to the point of death.[432] Our own view is that the objections to Ramsey's exceptions to the moral prohibition against killing are indeed compelling, especially those of McCormick and Jonas. Self-consciousness is indeed more arguably the characteristic sign of human existence than is the ability to communicate, and, since we do not and probably cannot know the exact borderline between life and death, the safest, most conservative course is to let the patient "die all the way". We would add as well, that from the theological and biblical perspectives we know of no good grounds for arguing that once a patient has become "inaccessible to care", the moral distinction between allowing to die and killing, and the moral prohibition against killing, become "matters of indifference". The

Bible does not after all say, "Thou shalt not kill, except when the patient has become impenetrably inaccessible to care".

Another of our bioethical tests to be applied to Ramsey's policy is that of parental decision-making authority. He acknowledges the parental right to be involved in the treatment decision, but endorses the practice of separating the decision about care from that of custody since they are very different and more time is needed for parents to decide about custody.[433] He also insists that in the eyes of the law all the parties with a role and relationship with a human being having a claim on their care, including parents and physicians, are guilty of offences ranging from abuse to manslaughter if they fail to provide the needed care.[434] In our view both these positions regarding parents meet the central concerns articulated in our bioethical test.

What can we conclude about the elements of openness, caution and self-criticism in Ramsey's policy? While his focus on the infant's objective medical conditions and his rejection of quality of life considerations is in many respects laudable and undoubtedly cautious, his medical indications approach would seem to err on the side of caution.

By rejecting all appeals to quality of life factors and not just the excessively subjective and arbitrary versions (involving for example "relational capacity" or "indicators of personhood"), Ramsey's policy fails to make some important distinctions. \ One is that between on the one hand qualities or conditions which connote "achievement" or the "earning" of treatment and care, and on the other hand those which are more in the nature of "burdens" on the patient. Rejecting as he does the whole concept of quality of life, he provides no assistance by way of criteria to limit its scope and exclude aspects and applications of the quality of life concept which clearly should be rejected in the light of Judeo-Christian bioethics. Since some degree of quality of life decision-making is undoubtedly justifed and here to stay, Ramsey to some extent deals himself out of contributing to the needed restraints on the scope of quality of life.

The somewhat doctrinaire and closed flavour of his policy is heightened by his insistence, seemingly against logic and common sense, that his "comparison of treatments" policy can be completely divorced from present and future conditions of life beneficial to the patient, and can be divorced from the notion that biological life is not an end or value in itself. Not to subscribe at all to the latter would seem to bring Ramsey, at least in principle, dangerously close to being a vitalist. Happily Ramsey in practice, according to some of his examples and conclusions, does in fact provide some openings to quality of life factors. He would undoubtedly deny that vehemently, but as indicated above, some of his statements seem to belie such denials.

The only point about which Ramsey could be said to be insufficiently cautious has to do with his exceptions to the prohibition against killing. As indicated above, there are some strong objections to that part of his policy, some of which lead to the conclusion that he pretends to far more certainty than is justified.

Is his policy tolerant, fair and interdisciplinary in nature? We would conclude that in some respects it is not tolerant at all of other positions, even when in substance some of those others are not in reality all that different. In our pluralist context that becomes a serious liability making his policy difficult to use as it stands outside the circle of those who agree with his very personal approach. The obvious example is his absolute and vehement rejection of quality of life considerations.[435] There is no doubt that he holds that view on the basis of his moral convictions, but he may also be too unwilling to probe his approach carefully to see whether some of his differences with others are more a question of language than substance, and whether there are more common elements than he realizes.

Insofar as Ramsey's policy seeks to exclude subjectivity and arbitrariness, it would seem to be a very fair approach, one likely to provide as much equality as possible when applied to the disabled newborns in a given hospital or unit. It may not be complete or open enough, but there can be little question about its fairness. The only aspect which could somewhat inhibit fairness if applied has to do with his exceptions permitting killing. As observed above, the determination as to when a patient has become "inaccessible to care" is open to some subjectivity given the fact that we cannot know for sure.

As for interdisciplinarity, Ramsey's policy is very aware of the role and contribution of both law and medicine towards his criteria and conclusions, and he does not hesitate to incorporate insights and positions from both of those other disciplines. He pays considerable attention to the legal duties and liabilities of various parties with responsibilities towards disabled infants, and in doing so implicitly acknowledges that there is a large quotient of public policy in treatment policies. There are in the final analysis legal limits as to what a policy can propose.

As well, Ramsey builds his policy to a large extent on the medical realities, and attempts to integrate into his own thinking and approach specific medical policies and views. The discussion and endorsement by Ramsey of Dr. Zachary's treatment policy is an example. At various points in his policy he indicates that determinations of various sorts fall within the proper role of medicine, not ethics. At the same time, he insists that the mandate of medicine has its limits - physicians are not for instance expected to alleviate all the world's suffering by exercising judgments outside their expertise and calling. As Ramsey notes:

> One can understand - even appreciate - the motives of a physician who considers an unhappy marriage or family poverty when weighing the tragedy facing one child against that facing another; and rations his help accordingly. Nevertheless, that surely is a species of injustice. <u>Physicians are not appointed to remove all life's tragedy</u>, least of all by lessening medical care now and letting infants die who for social reasons seem fated to have less care in the future than others.436

On the other hand it may well be that Ramsey views medical judgment and practice a little too mechanically. In urging the physician as he does to confine his attention and judgment exclusively to a comparison of treatments on the basis of present medical indications, and to ignore longer range conditions, qualities, benefits and burdens, one has the impression he is somewhat artificially restricting medical practice and judgment, focusing only on one stage and on the more mechanical aspects at the expense of treating the "whole" patient.

Our last test has to do with whether Ramsey adopts a participatory role. In view of the above we would suggest that Ramsey's policy reveals some elements of the theologian as "prophet" (i.e. the tendency to somewhat intolerantly denounce the views of others and to have one's own perspective incorporated to the exclusion of others), but also elements of the theologian as "participant". By the latter is meant one with definite convictions and points of view which are defended with vigour, but who nevertheless contributes, more or less as a partner, to a common undertaking with others. For all his intolerance and impatience with some aspects of other policies and their promoters (notably of course the notion of quality of life and those who use it), Ramsey does show much respect for the views of others on various matters, including theologians, physicians or lawyers. Insofar as he shows himself ready to debate with them and learn from them, his policy and the insights he provides do indeed contribute much to moral sensitivity on the matter of treating infants.

D. The Sonoma interdisciplinary policy

A rare example of an interdisciplinary policy proposal for treatment decisions involving seriously disabled newborns is that resulting from the "Sonoma Conference" in 1974. The conference was sponsored by the Health Policy Program and the Department of Pediatrics, University of California, San Francisco. Twenty people participated from the following professions and disciplines: pediatrics, nursing, economics, social welfare, psychology, law, philosophy and theology. The conference materials prepared before the meeting, discussed during it and further revised afterwards, were published two years later.[437] Subsequent to the conference a specific policy was formulated by two of the participants in the light of reflections and consensus during the meeting itself.[438] It purports to be an accurate reflection of the mood and tone of the discussions and decisions

The stated goals and questions of the Sonoma conference were the following:

> How, when and for what purpose should we employ the science and technology that burgeon in our times? For example, when should medical technology be used to its fullest in trying to keep a threatened

> infant alive, and when does the baby's probable future hold such grim prospects that it becomes more ethical and humane to withhold heroic measures?439

The participants believe that the conference and resulting policy make a significant contribution towards the ethical and policy issues of neonatal health care. We do not agree. While much in the background materials is interesting and important, the views of the participants and the moral policy itself underline some of the inherent limitations, difficulties and pitfalls of attempting to formulate consensual policies on value-laden matters in an interdisciplinary group. It is particularly disappointing in terms of the Judeo-Christian bioethical tests or norms we are applying in this thesis. To demonstrate the shortcomings of this effort we will focus on the answers provided by the participants to four questions they addressed to themselves, and to the ethical propositions comprising the core of the moral policy itself.

The four questions addressed to and answered by the participants were these:

1. Is it ever right not to resuscitate an infant at birth?

   (The participants answered unanimously in the affirmative).

2. Is it ever right to withdraw life-support from a clearly-diagnosed, poor-prognosis infant?

   (The participants answered unanimously in the affirmative).

3. Is it ever right to intervene directly to kill the dying infant?

   (17 said "yes" to active euthanasia in some circumstances, 2 answered "no" and 1 was uncertain).

4. Is it ever right to displace poor prognosis infant A in order to provide intensive care to better prognosis infant B?

   (18 said "yes, and 2 said "no").

As for the ethical propositions comprising the moral policy itself, they are the following (the emphasis is as in the original):

1. Every baby born possesses a <u>moral value</u> which entitles it to the medical and social care necessary to affect its well-being.
2. Parents bear the principal <u>moral responsibility</u> for the well-being of their newborn infant.
3. Physicians have the <u>duty</u> to take medical measures conducive to the well-being of the baby in proportion to their fiduciary relationships to parents.
4. The State has an <u>interest</u> in the proper fulfilment of responsibilities and duties regarding the well-being of the infant, as well as an interest in ensuring an equitable apportionment of limited resources among its citizens.

5. The responsibility of the parents, the duty of the physician, and the interests of the State are conditioned by the medicomoral principle, "do no harm, without expecting compensating benefit for the patient".

6. Life-preserving intervention should be understood as doing harm to an infant who cannot survive infancy, or will live in intractable pain, or cannot participate even minimally in human experience.

7. If the court is called upon to resolve disagreement between parents and physicians about medical care, prognosis about quality of life for the infant should weigh heavily in the decision whether or not to order life-saving intervention.

8. If the infant is judged beyond medical intervention, and if it is judged that its continued brief life will be marked by pain or discomfort, it is permissible to hasten death by means consonant with the moral value of the infant and the duty of the physician.

9. In cases of limited availability of neonatal intensive care, it is ethical to terminate therapy for an infant with poor prognosis in order to provide care for an infant with a much better prognosis.

The proposed policy also includes a series of "procedural recommendations", to some of which we will also refer in what follows, though they do not appear to constitute an essential element of the policy itself.

In these views and propositions (and in the supporting explanations and arguments) there is, first of all, little evidence that the participants were greatly influenced by the sanctity of life and quality of life positions proposed as normative in this paper. Though some were so influenced on an individual basis, the ethical policy itself and the numbers alone of those for and against certain propositions are at best ambiguous and vague. At worst they promote a subjective, arbitrary and "social" notion of quality of life.

The closest the policy comes to an affirmation of the sanctity of each infant's life and the duty to protect it is proposition one, above. But it is hardly emphatic or specific. The comment on that proposition does, however, add more:

> Moral value indicates that the infant, although unable to comprehend, decide, communicate, or defend its existence, requires by its very existence to be approached with attitudes of respect, consideration and care. The infant is designated as a being in its own right and morally, if not physically, autonomous. Its life is not merely a function of others.440

But the individual reasons behind the unanimously affirmative answers to question one, above, make it abundantly clear that the participants assigned the most varied, divergent and even mutually exclusive meanings possible to approaching a newborn "with attitudes of respect, consideration and care". The unanimously affirmative answer to that first question is not at all worrisome in itself, and in principle is quite consistent with our normative view of sanctity of life as having a non-vitalist meaning. But some of the reasons given for not resuscitating infants are more troubling. They range from those who agreed, but (only) if the baby is dead (as evidenced by tissue decay), or dying, or anencephalic, to those who agreed if the quality of life "will be intolerable", if the infant has "no chance (or small chance) of normal life", or if the infant "is clearly below human standards for meaningful life", to those who agreed if the infant's death "would minimize the suffering of the parents", or "avoid unbearable financial costs to the family", or "avoid emotional burdens on its siblings".

Given that range of reasons for not resuscitating, from proof of death to preventing emotional problems for siblings, it seems of very doubtful value and significance to indicate a unanimously affirmative answer to that first question. The consensus is entirely superficial - the participants are clearly not consenting to the same thing at all. Their qualifying reasons belie the apparent consensus.

This same feature of an apparent consensus to a very general proposition in reality masking a wide variety of qualifications and differences, characterizes many of the positions and proposals comprising this policy. More examples will follow. That may well be one of the inherent limitations of policy-making in a value-pluralistic and multidisciplinary context. The temptation always exists, some would say the pragmatic necessity, to sacrifice or cover a variety of strongly held views for the sake of consensus. But the resulting consensus bought at that price can be little more than skin deep, and the propositions so general that they offer little real guidance.

Essentially the same points could be made about sanctity of life and quality of life regarding the responses to the second of the questions to the participants, that regarding the withdrawal of life-support. Again the unanimously affirmative answers, but a wide variety of conditions and qualifications added by individuals. Here too the prevailing notion of quality of life strays very far from the objective medical conditions and benefit to the infant and expands that concept to include highly subjective and vague social quality of life formulations.

One such formulation supporting a yes to withdrawal of life support, qualifies the answer by saying, only if the infant's quality of life is intolerable, and then "defines" intolerable as: "the infant's life will predictably involve more suffering than happiness and it will probably be without self-awareness or socializing capacities". But what will count as "more suffering than happiness", why is that necessarily "intolerable", and how can that sort of future balancing of happiness and suffering possibly be "predictable" in infancy? And even if "self-awareness or socializing capacities" were not the vague and loose criteria they are, why should it be sufficient to withdraw life support if the infant will "probably" be without these capacities as opposed to "certainly" or "beyond a reasonable doubt"? Yet another of the stated conditions which invites subjectivity and arbitrariness is this: "If the infant will be markedly impaired with small chance for a normal existence". Among the several assumptions casually captured by that criterion is that "normalcy" is a readily known and agreed upon commodity, and that whenever it is lacking it disentitles one from life-support.

One finds in the responses of participants the same readiness to treat the <u>mentally and physically disabled infant unequally</u>, to provide in effect more rigorous tests to be met by the mentally retarded than by the non-retarded. For example, withdrawal of life-support is acceptable to one participant if it has suffered, "irreparable damage to crucial organs, especially the brain". Presumably the damage to the brain need not be serious, only irreparable. Another voted for withdrawal of life-support if the infant "has a genetic defect linked to severe mental retardation requiring institutionalization". Would that participant have voted for withdrawal if it had only a severe physical disability requiring institutionalization?

As for the specifically social quality of life criteria, the responses to all the questions indicate their importance to the participants. In answer to question one, [redacted]-resuscitation would be acceptable for example if:

- it would minimize parental suffering,
- it would avoid unbearable financial costs to the family,
- costs to the state of the infant's survival are considered.

In answer to question two, withdrawal of life-support would be acceptable if for example:

- its survival would threaten the family's quality of life,
- its survival would impose excessive costs on the family.

- the parents don't want a severely handicapped child or want a "more speedy death" for the dying infant.

In answer to question three, very similar social quality of life factors were mentioned in support of killing a disabled infant - parental wishes, financial burdens on the family or threats to the family's quality of life.

It seems reasonable to assume that the ethical propositions comprising the moral policy itself were largely influenced by and attempt to capture and gather the views of the participants such as those just referred to. If so, then proposition number six makes one very uneasy, especially the second part, "or cannot participate even minimally in human experience". That is clearly a formulation borrowed from McCormick, and the comment on that formulation does indeed attribute it to him. It is doubtful that McCormick would approve of his criterion and formulation serving as a summary of the very elastic, open-ended and social quality of life views contributing to this policy. As we noted above in discussing McCormick's policy, he does at least take great care to ensure that his "relational capacity" criterion focuses exclusively on the interests of the infant and conditions inherent in the infant. But used in the context of this policy his criterion seems to connote far more than he intended. One cannot necessarily fault McCormick for abuses by others of his position and formulation. But this extension of his position by others confirms our earlier hesitation about his "relational capacity" criterion, namely that because it is too vague it will be applied in subjective and arbitrary ways.[441]

As indicated above in establishing the elements of our sanctity of life test, a central duty which flows from that principle is the duty to save and protect life. From the Judeo-Christian perspective the bias is in favour of life, and not to save it, not to treat aggressively should be seen as exceptional and requiring very serious justification. As well, there is a moral duty whenever in the infant's interest to do more, not less, for the most disabled, most disadvantaged, most helpless of our infant neighbours; to compensate them rather than discriminate against them, even if this means a re-ordering of our societal priorities and resources to do so adequately.

But the tone of this policy promotes a quite different moral emphasis. Rather than a positive formulation promoting the above, this policy adopts as its central "medico-moral principle" that of "do no harm", as stated in ethical proposition number six. It is proposed as being more stringent than a positive principle (such as "preserve life") because positive formulations admit of exceptions and qualifications, whereas negative formulations admit of no exceptions and are universal.[442] That may be so, but exceptions to a positive formulation do not necessarily threaten or weaken the principle at all, and negative formulations tend to connote a minimal morality, a reductionist ethic.

That this is in fact the case here becomes apparent from the definition given by the authors to "harm" in the disabled infant context as found in ethical proposition number six. The ultimate harms in medical and other contexts are normally thought of as neglecting, abusing or killing patients. But this policy turns the word inside out by saying that efforts to bring aid by sustaining life or providing intensive care (for babies unable to survive, or who are suffering severe pain, or who lack capacity for human relations) are the real harms of interest to a treatment policy.

No doubt bringing (treatment) aid can sometimes itself inflict needless further suffering on an infant. But it does appear strange to say the least that a moral policy does not even mention within its definition of harm the more obvious, more ultimate, more Judeo-Christian meaning of harm in this context - the denial of life-saving aid to salvageable infants (despite alleged burdens to others or future uncertainties), or the denial of life-improving aid for unsalvageable infants (who cannot have years added to their life, but at least life added to their years).

The same reversal of the expected emphasis is to be found in the ethical propositions referring to the use of "limited resources" (proposition four) or "limited availability of neonatal intensive care" (proposition nine). Here too there is a missing balance and more than a hint of minimal or reductionist morality. What is missing from proposition four from the perspective of our Judeo-Christian bioethical norm is any hint of an appeal to compensate those in most need, to do more (as a society) than strive for "equitable apportionment of limited resources among its citizens".

The proposition seems to assume that the meaning and application of "equitable apportionment" is self-evident, and implies in the context of the whole policy that some "master resource-allocator" is ensuring that everyone gets an equal amount of health resource money. Of course that is not the case. It is in fact generally the case in our society that the rough and ready allocation principle in practice (at least for life-saving resources) is "to each according to his need". That operating principle is, in effect, essentially reflective of our Judeo-Christian ethic, whether health planners are conscious of that or not. That being so, to attempt to impose on disabled newborns (alone) a principle of strict equality in the division of emergency health resources would be clearly discriminatory, and would in fact take away from them resources they presently have. The disabled newborn infant is obviously given more health resources than the non-disabled infant. But unhealthy children and adults are also given more than their healthy counterparts.

As for proposition nine, it somewhat strangely introduces the concept of "triage" into neonatal intensive care. That procedure is normally confined to a military or civil disaster, and involves dividing casualties into those who will not survive even if treated, those who will survive without treatment and those who need treatment in order to survive (the priority group). As well, those with special skills needed in the disaster or who can be patched up quickly are given first priority within that last group. In such disasters, the fact of limited resources is one consideration leading to triage, but the major factor is the urgent need for people with needed skills to help an army or a community to restore function, communication, etc.

In view of all that, triage seems a somewhat strange approach in a neonatal unit. In the first place, in our society at least, conditions can hardly be described as akin to a disaster. Resources are generally not so limited that choices have to be made between salvageable infants. And it is obviously impossible to think of the infants themselves as having abilities and skills needed in a disaster, to the extent that those most needed are treated first.

But the reference to limited neonatal care resources and the hint of special disaster provided by proposing triage, manage to further underline the policy's general tone of restricting rather than expanding the care we give to disabled newborns. The impression is left that the authors of the policy conceive of neonatal care as quite unique in the range and stages of medical care, a form of medicine which is generally speaking an excessive burden on society and where special rules are needed and justifiable. If the triage rule threatens, as it does, the traditional notion that all humans are independent and equal, so be it. After all we have here a special "disaster situation". These are, after all, only disabled newborns, not adults, so triage can be proposed for neonatal care. But the authors do not suggest it for all the other forms and stages of (also expensive and sometimes limited) intensive care for "poor prognosis" adults. The same reasoning seems to be behind the call by the authors (in their commentary on the ethical propositions) for a degree of State planning and efficiency not proposed for expensive and sometimes limited intensive care directed to "poor prognosis" adults. Their explanation is that:

> ... the interest of the State can be invoked as an ethical consideration since the State has an interest in the recognition of values, in fulfillment of responsibilities and duties, in the fair and efficient distribution of benefits, and in the promotion of a healthy population.443

In the context of this policy, one fears that "fair and efficient distribution of benefits" and the "promotion of a healthy population" are meant to be earned at the expense of some disabled newborns. The first part of the fourth ethical proposition (listed above) speaks of the State's responsibilities and duties regarding the well-being of the infant. Surely the well-being and interests of disabled infants would be better served by ensuring that enough neonatal intensive care is made available so that both the "poor prognosis" and the "better prognosis" infants can be given appropriate care, rather than imposing a triage approach and forcing a selection between them.

What of our bioethical test prohibiting <u>euthanasia</u>? This interdisciplinary policy is somewhat ambiguous in the relevant ethical proposition (number eight), but it most certainly does not rule out killing. Referring to infants "beyond medical intervention" or in continued pain and discomfort, the proposition affirms that, "it is permissible to <u>hasten death</u> by means consonant with the moral value of the infant and the duty of the physician". This appears to be only a softer, more ambiguous version of the straightforward question addressed to participants (in question three): "Is it ever right to intervene directly to kill a self-sustaining infant?".

The answers given (12 "yes, 2 "no", 2 "uncertain") cover essentially the same wide range of reasons as the first two questions, though with a number of additional ones as well.[444] Those who say yes, do so for example if:

- it is "irretrievably dying a lingering death",
- it is "defective and unwanted by parents and un-needed by society",
- it has a flat EEG,
- it is anencephalic,
- it has Down's syndrome,
- it threatens the quality of life of the family or parents,
- the parents' consent,
- there is prior review and consultation,
- the nursing staff will not be demoralized.

The authors' comment on the eighth proposition begins by noting that the question of active euthanasia "is far from settled". It would have been more accurate to say that not everyone agrees about it. It certainly is settled for most people, for the most part (it would seem) people are either against it (absolutely), or for it (under certain conditions). From the perspective of our Judeo-Christian bioethical norm it is settled, and on the side of prohibiting it without exception. Not only does this policy leave the question open, but it provides a clearly discriminatory reason why euthanasia should be in effect a less serious matter when it is newborns being killed as opposed to adults. They write:

> We suggest that there may be a significant moral difference between an <u>infant</u> whose therapy has been terminated and an <u>adult</u> whose condition is diagnosed as hopeless ... For the adult, the time intervening between verdict and death may be of great personal value. For the infant, the intervening time has no discernible personal value.445

But while that infant obviously has no memories, plans or matters to arrange before dying (or being killed), surely it is presumptuous on our part to interpret and limit the value of life by the amount of time it has lived or can live. Certainly from the Judeo-Christian perspective there are no grounds whatever for assigning less value to the intervening time between the stopping of therapeutic treatment and death of an infant, than the period between verdict and death for an adult. As insisted upon many times in what precedes, only because therapeutic care stops for an infant for whom it would be useless, does not mean we abandon care. What remains is the continuing obligation to provide the best care we can for the time remaining. Merely because the intervening period has no <u>discernible</u> (i.e to <u>us</u>) value, does not mean there is none. To assign a value to that period for adults but not for infants is in the final analysis only another example of promoting the inequality of the disabled newborn.

As for the parental decision-making authority test, the policy itself does insist upon parental responsibility for the welfare of their child, and the duty to inform and counsel them. The second of the ethical propositions states: "Parents bear the principal moral responsibility for the well-being of their newborn infant". And the sixth of the "procedural recommendations" states in part:

> Parents at risk should be counseled about the possibilities. Since they bear primary responsibility for their infant, explanatory and supportive counseling is mandatory before and, in the event of a sick infant, after birth.446

But the policy is at best ambiguous about the scope and limits of that authority. Ethical proposition number seven (in the above list) does at least foresee the possibility that the physician and parents might disagree about medical care. But neither the ethical propositions nor the procedural recommendations refer to any moral or legal limits to the options from which parents may choose. There is an apparently deliberate ambiguity on that score.

If, however, we refer to the participants' responses to the four questions (listed at the start of this section), there is apparently no ambiguity at all in the minds of many of them. Their answers make it quite clear that parental decision-making authority is not only primary, but without limits. As well, consideration for the welfare of parents takes precedence over that of the infant, in the opinion of many participants. It is for instance acceptable to some that an infant not be resuscitated if the infant's death would minimize the suffering of parents. It is acceptable to some that life-support be withdrawn from a "poor prognosis" infant if that newborn is unwanted by the parents or if the parents want a "more speedy death". It is acceptable to some that an infant (including a Down's syndrome baby) be directly killed if the quality of parental life is threatened, or if the infant is unwanted by the parents.

In the light of those views one is tempted to conclude that the "well-being" of their newborn infant is in effect whatever parents say it is, and that the well-being of the infant, including its right to life, takes second place to the interests and wishes of the parents. Those views also have implications for ethical proposition number three about the duty of physicians: "Physicians have the duty to take medical measures conducive to the well-being of the baby in proportion to their fiduciary relationships to the parents". But if parental wishes and consideration for parents can take precedence even over the right to life of the infant, that proposition must in effect mean that, "physicians have a duty to look after the baby's well-being, unless the parents do not wish it or their own interest would be thereby threatened". If that is so, disabled newborn infants would certainly be in still greater danger than they already are should what is now only the abusive practice of (some) physicians, now be formally endorsed by a rule.

We find nothing in this policy to support the important practice referred to earlier whereby in dealing with parental decisions, the treatment decision is to the extent possible kept distinct from decisions about custody. They are in fact two quite different matters.

Is this policy sufficiently open and cautious? In our view it is inadequate on both counts. It purports to be a fresh response to new challenges of medical technology and the consequent need to determine more clearly the relevant rights, interests and benefits, particularly those of the disabled infant. In reality this policy speaks in very general and ambiguous terms, and provides few clear indications of its motivating principles or priorities, and the rights, benefits and interests of the infant are left very vulnerable indeed by this policy. It is not in other words an open policy, open that is to new challenges and possibilities, providing a careful weighing of relevant principles and values.

One of its shortcomings in this regard is precisely that the "ethical propositions" are more in the nature of recommended "medical practices" than affirmations and a ranking of principles and values. It is more a statement of how to manage cases than of the basic principles and priorities which should underlie that management. Statements about practice and management are not of course out of order in a treatment policy, but in a "moral" policy, as this purports to be, they should be the second stage, and linked to the ranking of principles and values on which they depend.

As it is, we have essentially a list of medical practices or policies with no clear indication of their ethical roots and scope. In view of the diversity of individual views evidenced by the responses of the participants to the four questions, it may well be that no agreement was possible on what principles, rights and values should predominate and how they should be balanced and ranked. If, as one suspects, that is indeed the case, and that the somewhat vague, open-ended generalities of the propositions were the best they could do, then we may have clear evidence of one of the major difficulties inherent in such interdisciplinary policy-making efforts - that of going beyond platitudes and producing a policy with some ethical teeth.

The general absence of limiting and balanced principles upon which to draw some lines and put some substance into terms such as the "well-being" of the infant, or "hastening" its death", or "means consonant with the well-being of the infant", also gives the "ethical" propositions a generally incautious flavour. The policy as worded claims a great deal, e.g. that death can be hastened (presumably even by euthanasia), that the triage approach is acceptable in neonatal care, that the real and important harm in neonatal care is not abusing or killing a newborn, but treating a child who cannot survive or cannot experience, etc.

Combining the ethical propositions with the actual views of the participants, a disabled child would not be overly encouraged by the generally altruistic tone of the policy. The interests of parents and society seem to be the real criteria for some participants, and this policy as worded could accommodate that view all too easily.

This interdisciplinary policy does not fare well when tested for fairness. It is difficult to see how it could encourage equal protection for the rights and interests of all the disabled newborns to whom it might apply, or how it could promote fairness in the care and protection extended to both infants and adults. A major justification for treatment policies is, after all, that of establishing some limits to arbitrariness and the subjectivity of the decision-makers, both of which put fairness at risk. But if the policy itself is too vague and ambiguous it can defeat its own purpose. It may even make things worse by providing a sort of formalized approval and blessing for the wide variety of personal views and approaches which a very general guideline can too readily accommodate.

Among these general and open-ended formulations are for instance the criteria of "minimal participation in human experience" (ethical proposition six), or "a life marked by pain and discomfort" (proposition eight). Those criteria may not be so threatening in themselves, but since they are presumably meant to accommodate the wide variety of personal views represented in the participants' answers to the four questions, we have a clear sign of just how elastic and arbitrary their use would likely be. On the basis of those views, the criteria for allowing non-treatment or "hastening death" which are found in the ethical propositions, (e.g. "minimal participation in human experience", "pain or discomfort", "intractable pain", "beyond medical intervention") may presumably be translated into some of the still looser and more subjective grounds to be found in the participants' responses, e.g., "if the infant has no chance, or small chance for normal life", "if the infant is below human standards for meaningful life", "if the infant has Down's syndrome", "if the infant is dead", "if the infant suffered irreparable damage to the brain".

But this policy is more than just vague and ambiguous. It is also unfair in that in a number of ways, both by what it does say and does not say, it comes down against the right to life of disabled infants in favour of lesser interests of other parties. Its openness to euthanasia, discussed above, is one example. By leaving itself open (in proposition eight) to hastening death by means of killing, by noting in the accompanying comment that the subject of active euthanasia is "far from settled", the moral prohibition against killing is in effect removed. It is only one more step to accepting as legitimate reasons for both non-treatment and killing the sort of views actually found in the participants' responses, e.g. if the baby's death would avoid parental suffering or financial costs to the parents, if the parents prefer its early death, if its continued life threatens the family's quality of life, or if the costs of treatment are too high for society. Should those grounds for killing prevail, as this policy implicitly permits, then the lesser interests of other parties would prevail over the infant's right to life. Clearly that is an injustice of the most fundamental kind.

Other examples of unfairness exist as well. One involves the policy's position on limited resources, already discussed above. As noted, that position implicitly discriminates against the disabled newborn. There is as well, the "proportionality" aimed at in ethical proposition three between the physician's duties to the newborn and duties to the parents. As formulated, without any reference to the particular rights of the child and the parents which are at issue, and which ought to have priority in what circumstances, that proposition is open to an interpretation that a salvageable baby's right to life may have to give way to parental wishes and parental inconvenience.

As for the test of interdisciplinarity, we have already indicated what appears to be the major shortcoming at least as regards this policy - the tendency to submerge and accommodate many divergent moral views and professional perceptions within vague and general formulations open to very different and opposed interpretations. Whether this is due more to the variety of moral views as such or to the differences in professional perspectives is impossible to say.

One result is that important and strongly held individual moral positions and differences do not stand out sharply in the policy itself - they are pushed back out of sight (though in this case they were accessible thanks to the participants' responses to the four questions). But those divergent individual moral views and professional perspectives, if strongly held, are not likely to go away. Instead of appearing "up front" in the policy itself they will no doubt have the same effect indirectly - the general propositions of the policy will very likely be interpreted by each in the light of their own individual morality and professional stance. If so, then the final result will be one very general policy in theory, one which does not come to grips with the really difficult and urgent issues, a policy to which no one pays much attention, and then many individual treatment policies applied in actual practice. In other words, nothing much will have changed.

Another result demonstrated by this particular interdisciplinary policy effort is the apparent tendency to reduce the scope and moral intensity of the policy to a minimal morality, to the least contentious issues and positions, as much as possible reducing considerations of public policy and morality to those of merely private morality. Some examples of that tendency were already indicated above. But an example directly relevant to interdisciplinarity itself is found in proposition seven with reference to the role assigned to law and courts.

That proposition states: "If the court is called upon to resolve disagreement between parents and physicians about medical care, prognosis about quality of life for the infant should weigh heavily in the decision as to whether or not to order life-saving intervention". The worrisome aspect of the statement is not necessarily the reference to quality of life prognosis, but to the implication that the role of courts and law is only that of intervening to resolve private disputes between parties. No other role or value is assigned to courts and law elsewhere in the policy.[447] Two assumptions seem to be at work here. First of all that a treatment decision involving a disabled newborn is essentially and only a private matter between physician and parents, the court called upon to intervene when they cannot agree. Secondly, that as long as parents and physician do agree, whatever the grounds for the decision and whatever the outcome for the child, courts have no business intervening in this essentially "private" agreement.

But as already stated a number of times in this thesis (and as we will indicate in greater detail in the next chapter), these treatment issues involve far more than just private morality or private agreements between parents and physicians. There is a large quotient of public morality and public policy as well given that the lives and health of children are at stake, and it is the role of the State, in part via law, to protect their lives from negligence and abuse. That does not of course mean that the law and courts are or should be involved in all these decisions. Not at all. As far as possible these decisions should be left to the privacy of parents and physician, and in most cases the best interests of the infant will no doubt be well served by them. But the law as the ultimate expression of societal tolerance and protector of both individuals and essential institutions from harm,[448] has something to say about the outer limits of what society is prepared to accept. It also has a responsibility to sometimes intervene to protect rights and persons whether invited to do so or not by parties in disagreement.

The last of our normative bioethical tests to be applied is that of the participatory function of bioethics and bioethicists. It will be recalled that within what we have labelled the "participatory" model, the ideal theological bioethicist has definite moral positions and defends them vigorously, but conceives of his policy-making contribution in an interdisciplinary group as that of a partner. As such he is also ready to learn from others and to seek common ground wherever possible without sacrificing his own moral convictions. Our question then is, did the theologian involved in this particular effort (i.e. Albert Jonsen) in fact play a participatory role in the sense described?

Obviously we can only answer that question if we know the theological tradition and/or relevant moral convictions of the particular theologian or theologians in question. Only then are we in a position to see whether the policy to which a theologian contributed reflects to any degree the tradition and/or convictions of that bioethicist. As it happens we do know at least one such position held by Jonsen (along with his philosopher colleague and fellow participant, Garland), namely that he is emphatically against the killing of disabled newborns. This we know from one of the Conference's background articles written by Jonsen and Garland.[449] That being so, they were very likely the two who answered "no" to the question about whether it is ever right to directly kill a dying infant. Armed with that information we can only conclude that at least as regards active euthanasia, the theologian in this instance did not defend that conviction with vigour and/or success. The policy itself, as already noted, by no means excludes active euthanasia. On the contrary, the "hastening death" formulation of proposition eight could readily accommodate killing in the context of the whole policy.

One suspects his conviction against euthanasia may not have been defended with much vigour. How else explain the fact that it was Jonsen and Garland who wrote the policy and also the commentary in which they said the morality of euthanasia is "far from settled".[450] Assuming then that Jonsen was not persuaded to change his position against active euthanasia and continued to hold it, the only other explanation for his acquiescence with a policy which at best soft-pedaled that point, was his eagerness to produce and contribute to a consensual and interdisciplinary policy. But our question then is, how far should the theologian go in that direction? Does there not come a point beyond which one's own convictions and theological tradition should require that one bow out of the effort or explicitly dissent? We will leave a more global answer to that question until the concluding chapter; suffice it to say now that our answer is "yes" to the second question.

A hint that Jonsen may have been overly eager to compromise for the sake of consensus is to be found in the goal and expectation he provides for the whole exercise, namely that:

> when many individuals with diverse moral convictions face a series of decisions about similar cases, there should be a way to accommodate the diversity of private beliefs within some degree of broad agreement about how such cases should be managed.[451] [Emphasis added]

That such an accommodation and agreement is desirable, we fully agree. But that there should (always) be a way of actually achieving it given a diversity of beliefs would seem to be a largely utopian hope. Our examination of this interdisciplinary effort suggests that there can come a point in the search for agreement and consensus after which both can be achieved only at the (unacceptable) cost of either producing a policy which is too vague to be morally helpful and protective of the disabled infant, or by bargaining away a theological or personal conviction.

Chapter IX: Legal Policies

We turn now to the legal policies regarding the treatment of the seriously disabled newborn. Three preliminary points should be made at the outset of this chapter. The first is that this chapter cannot and does not pretend to be an exhaustive treatment of the position of the law on this subject. Given the size and complexity of this subject, involving as it should court decisions, legislation and legal analyses in many different countries and legal systems, a comprehensive treatment would require a separate thesis on that perspective alone. Given both space limitations and the bioethical focus of this thesis it is neither possible nor necessary to provide more than a summary of the legal stances on the matters of interest to us.

Which brings us to the second of our preliminary points. There are potentially a very large number of issues one could address under the general rubric of the law and the disabled newborn. But the particular normative bioethical tests being applied in this thesis justify narrowing the number of questions addressed to the law to matters of relevance to those tests. Accordingly, we will discuss the position of the law on these three related matters - the killing or active euthanasia of disabled newborns, the legal position on allowing seriously disabled infants to die (including the scope of quality of life considerations), and the role and limits of parental authority. Most of our other tests are included within one or more of these three, and will be touched upon as well. As it happens, those three questions are the ones which have received the most attention by courts and legal analysts in recent times, and the ones about which there is the most unanimity.

Thirdly, we will not find anywhere in statutes or court decisions a single, detailed and comprehensive legal policy covering all the legal rights, duties, liabilities and procedures involved in treating disabled infants. Case decisions for example actually decide only the relatively narrow question addressed to it by the parties (in civil actions) or the State (in criminal prosecutions). Courts do, however, provide a great deal of significant legal reasoning about related matters by way of background and reasons for their judgments. Child welfare and health protection statutes, and the Criminal Code, do not address explicitly or comprehensively the subject of disabled newborns, but one can readily apply many of their provisions to these infants. We will therefore refer under each of our three headings to various relevant court decisions, legal analyses and statutes.

A. Euthanasia and the law

A first and fundamental question concerns the legality of euthanasia. Our question here is. would the killing by act or omission of a seriously disabled infant, for instance for motives of compassion for the infant or its parents, incur criminal liability? The answer is yes, in principle it would. Whether such an act or omission does in practice lead to an actual prosecution depends upon a number of conditions.

Several conceptual and semantical points should be cleared up at the outset. First of all, in the legal context it makes little sense to distinguish between active and passive euthanasia (though it is sometimes done). From the legal perspective, what makes something illegal or not is not whether it was an act or an omission. Omissions can sometimes incur the same liability as commissions. There are especially two deciding factors as to whether an omission will incur legal liability. The first is whether or not one had a *legal duty* to provide what was omitted. If so, then *not* having done so incurs essentially the same liability as an illegal *act* which achieved the same result. The second is whether that omission of what one had a duty to provide was actually the *cause* of the result in question. If that result would have happened despite one's omission, then the omission was not its cause and implies no legal liability.

In view of the ordinary meaning of euthanasia, that is, "mercy-killing", there is therefore no legal point to distinguishing between "active" euthanasia (killing by act) and "passive" euthanasia (killing by omission). The legal issue is not whether one is killed by act or by omission, both being forms of homicide if there was a duty to provide treatment, but whether one's act or omission killed, or the disease alone. In our view it would contribute greatly to legal (and ethical) clarity if the qualifiers "active" and "passive" were banned forever from qualifying the word "euthanasia".[452] The important legal distinction is therefore between killing (by act or omission) and allowing to die (when there is no legal duty to do otherwise). The latter is the subject of the next section in which we will examine the conditions which can make an omission to treat legally acceptable as opposed to a culpable causing of death. What concerns us in this section is essentially the issue of euthanasia or killing, an act or omission which can be legally categorized as a form of homicide within the meaning of section 205 of our Criminal Code. That section provides that:

> A person commits homicide when, directly or indirectly, by any means, he causes the death of a human being.

We should add that accelerating death is also a form of homicide according to section 209 of the Criminal Code. Even though a person (including an infant) is already dying from a "disease or disorder", it is a criminal offence to cause a bodily injury which results in death by accelerating it. In the eyes of the law, therefore, one who hastens the death of a disabled and dying infant is not relieved of criminal liability for causing death by arguing that the newborn was already dying.

There is also another criminal offence which could apply in our context, though it does not fall within homicide. It is that of "causing death by criminal negligence", provided for in section 203 of the Criminal Code. It has been established for instance that if a parent of a minor child recklessly denied treatment to their child, thereby accelerating death, that could be an example of causing death by criminal negligence.[453]

The sanctity of life principle is undoubtedly the most fundamental of principles in law, especially in criminal law. Though not understood in a vitalist manner (as we shall demonstrate in the next section) respect for and protection of human life is fundamental to all modern legal systems. Whatever the cultural, social or political differences, on at least one point their laws will agree (though unfortunately sometimes selectively enforce), namely that one may not kill other human beings with impunity. A major portion of Canada's Criminal Code is devoted to offences against the person, the largest single portion of which is devoted to the various forms of homicide. Though the Criminal Code does not refer explicitly to euthanasia, in principle it could be murder (i.e. causing the death and intending to do so) or manslaughter (causing the death in the heat of passion or under provocation).[454]

But do newborn infants fall within the meaning of "human beings" whose killing is prohibited by the Criminal Code? Are newborns entitled to have their lives and health protected as fully as children and adults? As we observed earlier in this thesis, physicians do not normally refer to infants as anything less than human beings or persons. Nevertheless, we identified a tendency of many to give much more weight to parental wishes and burdens in the case of disabled newborns than they would in the case of children; to the point that some find in parental wishes or burdens justification for killing the former (even when salvageable), but not the latter. We suggested that whatever the conscious reasons, this implies the assumption that infants have less intrinsic value than others and may not even be persons.[455] Some philosophers argue quite explicitly that newborns are not persons in the full sense, but at best "potential persons", and that therefore disabled infants could be sacrificed if their continued existence threatens the "self-realization" of "existing" persons.[456]

But in the eyes of the law such assumptions and propositions are completely untenable. From the moment of birth a newborn infant, disabled or not, is considered a person in the full legal sense, and as such is entitled to full and equal protection of the law. For criminal law purposes, including the homicide provisions, section 206(1) of the Criminal Code makes that quite clear:

> 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...

If the existence of a legal <u>duty</u> to do something is one of the elements which can make an omission into a form of culpable homicide (rather than simply allowing to die), then what are those duties and who can have them? The legal duties of interest to us are those referred to in section 197 of the Criminal Code as the provision of "necessaries of life" to minor children unable because of age, illness or other causes to provide for themselves. What they involve are those things needed to preserve life, and it is clear in law that this can include medical treatment needed to preserve life.[457] Those who have legal duties to provide necessaries of life, are those who have these minor children "in their charge", either by virtue of their family relationship (i.e. parent, foster parent, or guardian) or professional relationship, the latter including physicians.[458] In principle then, should physicians or parents fail to provide necessaries of life, e.g. life-preserving medical treatment, to a disabled but salvageable infant, with the result that the infant dies, they are liable to prosecution for homicide.

But cannot parents relieve physicians of their legal duties in this regard, can they not extinguish the physician's obligations by withholding their consent to the life-saving treatment of their salvageable newborn child, and requesting that it not be treated? Not at all. The physician's duty to provide appropriate treatment can be founded independently of any contract with the parents of the disabled child to be that infant's physician. As Robertson affirms in this regard, the traditional tort doctrine would undoubtedly apply, namely that one who assumes the care of another, whether gratuitously or not, continues to have a duty to care if not doing so would endanger life.[459] In Canada, that duty has been incorporated and codified for criminal law purposes in section 199 of the Criminal Code:

> Everyone who undertakes to do an act is under a legal duty to do it if an omission to do the act is or may be dangerous to life.

That provision does not of course impose a duty on physicians to provide life-sustaining but therapeutically useless treatment, but it does provide a basis in criminal law for the physician's duty to provide treatment independently of his contract with the infant's parents.

The physician's duty faced with parental refusal of medically indicated life-preserving treatment is to seek to provide it regardless. He should normally do so by first of all reporting to the hospital or judicial authorities instances in which parental refusal to authorize treatment amounts in his medical judgment to child abuse or neglect. The source of the physician's duty to report is to be found in the provincial Child Welfare Acts, which impose a legal duty to report cases of parental neglect. If the court decides that treatment in this instance is indeed a "necessity of life", a guardian will be appointed and the treatment authorized despite continuing parental refusal.

It should be emphasized that a compassionate motive for killing by act or omission does not make the act or omission acceptable or less legally culpable. Motive is not an essential element of crimes in Canadian criminal law, or in other common-law jurisdictions, so that compassion is of no legal consequence as regards guilt or innocence (though it may well affect the sentence). All that matters is whether or not one intended to cause death, whatever the motive, be it compassion, vengeance or personal gain. That being so, to kill an infant out of compassion for the suffering child and/or for the parents, cannot serve as justifying reasons in the eyes of the law.

The specific matter of pain-killing drugs and other forms of palliative care which can also hasten death should also be noted. It is generally acknowledged that drugs or other forms of care can be provided in the doses required to adequately control an infant's pain and discomfort, even though death might thereby be hastened.[460] If death is thereby hastened, that is a sometimes inevitable by-product of adequate care. What makes such treatment good medicine and not homicide is when the intent is to relieve the (newborn) patient's discomfort, not to kill it, and the dosage is proportionate to the pain and discomfort. What would make such treatment a form of culpable homicide is when a sedative palliative treatment is administered which hastens death and is clearly excessive for purposes of only comforting the patient. By this standard, those physicians such as Lorber who apparently over-sedate some of their seriously disabled infant patients in order to starve them and achieve quicker deaths, undoubtedly incur potential criminal liability for homicide.

The mere fact of potential criminal liability in the ways discussed above, does not of course mean that parents, physicians or others will in fact be prosecuted or prosecuted successfully. In the relatively rare cases in which parents have been prosecuted for killing their defective child, they have usually (though not always) been acquitted.[461] It would appear that no physician has yet been prosecuted for killing by omission, though a physician was recently charged with murder, allegedly for killing a disabled infant by the administration of a massive overdose of morphine. (See below, pp.432-434). In the rare instances where charges have been laid, the acquittal rate has been high.[462]

Several factors have been suggested to explain both the rarity of prosecutions and the frequent acquittals for euthanasia by act or omission. One is the high standard of proof required in criminal law ("beyond a reasonable doubt") combined with the difficulty of proving causality, that is, that the act or omission of the accused physician caused the patient's death. In some cases the evidence indicated that it was the disease or disability which best accounted for the patient's death, and/or that stopping of life-support measures was justified given that the patient was for example deeply comatose with no chance of recovery. In other words, omissions are often held to be quite acceptable legally, more in the nature of "allowing a patient to die" from his disease than a failure to perform a legal duty. An example is a recent California case in which two physicians were charged with murder for stopping life-support measures for a comatose adult patient (with the concurrence of the patient's family).[463]

Another example leading to a charge of murder, in this instance not by omission but by commission, involved the alleged overdose by morphine of a seriously disabled newborn girl in an Edmonton, Alberta hospital. This case as well illustrates how the major and most difficult element in prosecutions is that of proving causality. Candace Taschuk was born in an Edmonton, Alberta hospital in October, 1982. She suffered from serious brain damage and convulsions. Sixteen hours after her birth a foreign doctor practicing at the hospital administered a massive overdose of morphine to Candace, 15 mg of morphine, fifty times what was considered to be a "normal" amount. It was administered in two separate injections in each of the baby's thighs. She died forty minutes later. Shortly afterwards the physician told the Registrar of the (Alberta) College of Physicians and Surgeons what he had done, and that he had intended to kill the baby out of compassion. The College suspended his licence as a result. As well, the two nurses who actually administered the morphine on the physician's orders were suspended by their nurses' association. But by the time the incident came to the attention of the Attorney General's Department some months later, the physician had fled the country and returned to his own land.

A Provincial Court judge was then appointed to do a formal inquiry to determine whether the morphine dosage administered by that physician actually killed Candace. This was to be a preliminary step to assist in the decision as to whether or not to lay charges. It was never in dispute that the physician in question administered the dose, that it was potentially lethal and that he intended to kill the baby. The physician had admitted all this to the Registrar of the College. But the judge heading the inquiry concluded that because Candace was dying from other causes in any case, and a complete autopsy was not conducted after she died, her death could have been caused by the morphine, by asphyxia or a combination of both.[464] The physician was nevertheless charged with first degree murder in the baby's death, as well as eight other charges ranging from bodily harm to attempted murder. Attempts to extradite him and have him returned to Canada for trial are apparently continuing.

A second factor to be reckoned with, at least in cases which could be construed as homicide _by omission_, is the need to prove one of the required elements of a criminal act, that is, the _mens rea_ or wrongful intention. Since in practice the physician has the responsibility of determining whether a treatment is ordinary or extraordinary in the circumstances, he could in some cases escape prosecution by arguing that the treatment omitted was extraordinary and therefore not within his legal duty to provide. In some cases, even if the physician "intends" that the infant not survive, if the withholding could be construed as a conscientious withholding of what in those circumstances was extraordinary treatment, a prosecution would not (and should not) succeed.[465]

A third reason for the rarity of prosecutions for killing by act or omission in neonatal units is the obvious one that whatever the actual frequency of such incidents, it would not be easy for law enforcement authorities to find out about them. A number of factors could account for that. First of all, many cases of selection for non-treatment do in fact fall somewhere in the grey area between causing death by failure to perform a legal duty (hence homicide) and simply allowing to die (because therapeutic treatment will serve no purpose). In such cases it is most unlikely that any one would report a potential abuse to the authorities, especially when the parents are in agreement with the non-treatment. Secondly, provision already exists for parents or physicians to seek a court's ruling before the event should one party or the other feel that a proposed course (for or against treatment) might be abusive and illegal. Thirdly, given the general disregard of physicians for the legal implications of selecting infants for non-treatment (an attitude we noted earlier when examining the results of polls and surveys) it is hardly surprising that physicians do not themselves tend to report incidents of potential criminality or abuse involving other physicians. The general attitude of most physicians appears to be that these decisions are essentially medical, not legal at all, and should be decided in private in consultation with the infant's parents; if abuses do take place and do become known in medical circles they will normally be handled within their own self-disciplinary medical structures.[466]

The rarity of criminal prosecutions to this point for the killing of disabled newborns should not, however, be taken as a reliable picture of the future. We tend to agree with those who predict that as the practice of selecting infants for non-treatment becomes more widely acknowledged and known, the pressure to prosecute will increase.[467]

B. Allowing to die, quality of life and the law

The above considerations were not meant to suggest that the law demands that the lives of all disabled infants must be actively supported up to the last breath. Despite its clear bias in favour of life, the law in this regard is not in the final analysis "vitalist" in principle or in practice. While it prohibits absolutely and unequivocally the killing of disabled newborns, it does acknowledge that there are circumstances when therapeutic and life-supporting treatment may cease or not be initiated, and the infant patient be "allowed to die". Our question in this section then is, what are the legally acceptable limits and criteria which should apply in making these decisions, what weight does the law give to the patient's condition, to the patient's predicted quality of life?

At first sight it may well seem that the law, at least the law as written, is indeed vitalist, and that treatment, once begun, may not be stopped until the patient's death. A provision of the Criminal Code referred to above if read in isolation seems to support that conclusion, namely section 199, "Everyone who undertakes to do an act is under a legal duty to do it if an omission to do the act is or may be dangerous to life".

Taken literally and in isolation that could mean that the law requires the use of what in effect would sometimes be useless aggressive or therapeutic treatment, the continuation of which may be working against the patient's best interests, by inflicting pointless and serious additional suffering or merely prolonging the dying process. As the Law Reform Commission of Canada and others have clearly demonstrated, that provision of the Criminal Code must be read in context.[468] If that is done, it becomes clear that section 199 must be interpreted against the background of the central legal standard of conduct, the <u>reasonableness of the act under the circumstances</u>.[469] Further clarification and qualification is to be found in the criminal negligence provisions of the Criminal Code. They establish a specific standard directly relevant to our context and issue. The law (in this case section 45 of the Criminal Code) does not consider every act or omission endangering life to be criminally negligent, but only those in which one "shows wanton or reckless disregard for the lives or safety of other persons".

While there is admittedly some ambiguity in this regard in the law as written, which in our view argues for some clarification and reform of the Criminal Code,[470] there is considerably less ambiguity about the permissibility and criteria of non-treatment in the law as practiced. It is especially in the judgments of courts and their reasons for judgment that we find the material from which to construct the criteria which the law has thus far applied in deciding (before or after the event) that an omission to treat was (or would be) either a violation of the duty to provide necessaries, or a legitimate instance of stopping or not starting therapeutic treatment because it has become useless. We will therefore turn now to some of those cases.

Before looking at some specific decisions of courts, we will first of all summarize what in our view are the main principles and criteria governing non-treatment from the legal perspective. The decisions and legal analyses to be discussed below will amplify and provide the support for these criteria. We propose four general considerations or principles, and four specific justifications for non-treatment. First to be listed will be the general considerations.

1. The first of the general principles central to the concerns of law is that decisions not to continue or begin therapeutic or life-support treatment for a disabled newborn must be made in the best interests of that infant. Liability for the death of a salvageable child as a result of its selection for non-treatment, is especially likely if treatment is withheld in the interests of persons or considerations other than that child. Given the commitment of law, especially criminal law, to the sanctity, preservation and equality of individual human lives, there is no support whatever to be found in the law for trading off a salvageable newborn's right to life for the lesser interests of others, be those interests the burdens on parents, health professionals or society. As will be discussed below, there is no legal obligation for parents to keep custody of a disabled newborn they are unable to care for, and legal mechanisms are already available and should be improved to allow those parents to terminate their rights and duties to their newborn and transfer them to the state. The legal emphasis on the best interests of the infant does not therefore imply no legal interest in the plight or rights of the parents, and is premised on the need to separate the treatment decision from the decision about custody and subsequent care.

2. The second of these general considerations is the related one that the law is somewhat skeptical of arguments and criteria defending the non-treatment of a disabled infant or child on the grounds that this would be in the best interests of the child, that treatment or continued life-support would impose unbearable burdens on the infant now and in the future. There is a tendency to sometimes clothe self-interest in the garments of altruism, or to make one's own subjective (and non-disabled) perspective the rule for others. Therefore courts understandably place a heavy burden of proof on those advocating non-treatment, whether in hearings to seek court authorization before the event, or criminal and civil proceedings after the event. Courts are not easily persuaded by arguments made by healthy and normal persons to the effect that an infant with this or that disability would clearly not want to live with the limitations or pain which would result if the infant were allowed to live. Such grounds are sometimes accepted, but they are subjected to very careful scrutiny. Should a court not be persuaded it will reply that the perspective of a healthy, normal person cannot be assumed to be that of a seriously handicapped infant with few or none of the experiences or expectations of the non-handicapped. The disabled patient may well see even a severely limited and institutionalized life as preferable to no life at all.

3. The third of the general legal considerations has to do with the <u>accuracy</u> of the prognoses and criteria used by a physician or a neonatal unit in selecting infants for non-treatment. The attitudes, practices and treatment policies of physicians noted and evaluated earlier in this thesis tend to confirm this observation by the legal writer, Robertson:

> [S]everal facts suggest that many more infants than would meet the criteria for justifiable selection for non-treatment are not being treated. First, most of these decisions are not made on the basis of articulated, clear criteria. They vary with the doctor, the hospital and a mixture of factors not explicitly stated. Secondly, there are no legal or other checks on the discretion of doctors and parents. There is no required decision-making procedure, and though non-treatment currently would be illegal and criminal in nearly every jurisdiction, the law has not been enforced and is not much of a check. Thirdly, those decisions are often made in a highly emotionally charged setting...471

Clearly there is a risk posed to the lives of infants who should be treated and saved, by treatment criteria which are too subjective, two loose, too unclear or applied with too little attention to specific confirmatory procedures and processes. That risk gives rise to this third general legal consideration, namely that the <u>treatment criteria themselves</u> must be <u>formulated and applied</u> in a manner which precludes as much as possible the danger of not treating and letting die infants who should not have died.

As regards confirmatory processes, this legal consideration would appear to support and encourage not only second and third opinions, but also the involvement of hospital committees to review tentative decisions in the interest of reducing the frequency of errors. It would also discourage non-treatment decisions from being made too early, since reasonably accurate diagnoses and prognoses sometimes require time. An example of a treatment policy which in a number of respects would fail this legal test is that of Dr. Lorber. He himself admits that applied as rigorously as he does and on the first day of life, some infants not treated turn out not to have met even his own criteria for not treating. But by the time he is aware of that the infant is either dead, or alive but in much worse condition than if treated at birth.

4. Even though there are some legally acceptable reasons why therapeutic or life-support treatment may sometimes stop or not be started, there would appear to be no legal justification for denying that infant <u>needed palliative care</u>. This would not be care needed to prolong or save the infant's life, but to relieve as much as possible its pain and discomfort or to maintain or improve the infant's basic functions for whatever time is left to it. Since the physician still remains that infant's doctor after a decision not to treat therapeutically, he continues to have legal obligations to provide care, just as

he would to a child or adult determined to be beyond the help of therapeutic medicine. Not to provide that care could undoubtedly be construed in the eyes of the law as a form of abuse or neglect. As such, such omissions could incur liability under (provincial) child welfare legislation.

Turning now to the specific justifications for non-treatment, there are arguably four which are consistent with the legal insistence upon the best interests of the infant patient and the equal respect due to each. The four conditions or circumstances are these:

1. If the infant has an irreversibly life-threatening condition, and death is imminent, and no available therapeutic or life-saving treatment can do more than prolong for a short time the dying process. It is highly unlikely that the law imposes a duty to treat in such a case since that appears to be contrary to the child's best interests.

2. Whether irreversibly dying or not, if a newborn has suffered such extensive brain damage that it would not be reasonable to think of this child having any interests at all. Should a life-threatening but correctable complication arise, it is difficult to see how any liability could incur if that complication is not treated and death follows. There is of

course no mathematical formula by which to decide which cases manifest enough brain damage to be selected for non-treatment. There is little doubt that the anencephalic child, with most or all of the brain missing would be in this class. But there is also no doubt on the basis of legal judgments that the sort of disability which would not normally fit into this class is the infant with Down's syndrome.

3. Whether or not irreversibly dying, those newborns who have a condition causing them extreme and irremediable suffering and discomfort, may also constitute a "class" of patient who can be legally selected for no treatment should a life-threatening but correctable complication arise. Though their lives can sometimes be extended at least for short periods, it could not be said that such infants have an interest in continuing to live. In these infants the mere struggle to survive and cope with their discomfort requires all their energies and precludes the possibility of any real happiness or self-realization.

4. If excessively burdensome qualities would be caused by or associated with the means available to sustain an infant's life. Sometimes the only form of treatment available for a particular problem is not only useless, but likely to make things much worse. An example is the closing of the lesion

in some cases of spina bifida, cases in which the wound is not likely to heal but become worse. Another example might be an infant who could be saved by treatment but for whom there does not exist the highly sophisticated supporting care or technology needed afterwards. To treat in such a case could sometimes be unreasonable ethically and legally, and clearly not in the best interests of that infant.

We turn now to a brief consideration of a number of legal cases in order to further clarify those conditions. One such is the Quinlan case.[472] Though the subject in that case was not a disabled infant but a teenage girl, several aspects in that judgment are directly relevant to the seriously disabled infant. Karen became comatose, possibly as a result of drug overdose. When determined to be in what was described as a "chronic vegetative state", for which there was no known cure or means of improving, her parents petitioned a court to authorize the cessation of life support, which the court did authorize.

Four points in the judgment are of particular interest to us. One is the court's affirmation that though she was incompetent and irreversibly comatose, she retained the right to have treatment withdrawn, though of course it would have to be exercised on her behalf by someone else.

Secondly, the court affirmed that <u>quality of life factors</u> are legally acceptable criteria for decisions by families or guardians to continue or stop life-support. In this regard the court spoke approvingly of those who do not "inflict an undesired prolongation of the process of dying on a patient in irreversible condition when it is clear that such 'therapy' offers neither human nor humane benefit".[473] The judgment goes on to affirm that the decision should depend upon the prognosis as to "the reasonable possibility of return to cognitive and sapient life, as distinguished from the forced continuance of that biological vegetative existence to which Karen seems to be doomed."[474]

A third and also relevant affirmation of the <u>Quinlan</u> court was the assertion that a "reasonable person" standard can, at least in a case involving these facts, be acceptable. The court stated in this regard that if the family decided in favour of the withdrawal of life-support, "their decision should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or those closest to them". The court appealed in other words to what most people would do and want as reasonable people. It did not, however, affirm that what we, the healthy, would do is <u>always</u> a legally acceptable standard for deciding what an incompetent disabled person would want. It makes perfect sense when the subject is irreversibly comatose and "vegetative" as was Karen, but as we will note below about another decision, that standard can be suspect when the damage is not as total or as readily determined.

A fourth point of interest was the Quinlan court's requirement that a hospital committee should confirm the prognosis of the physicians that Karen would not recover her cognitive and sapient functions. If such a requirement was imposed in the case of Karen Quinlan, in which the damage was far greater and more evident than in the cases of many disabled newborns selected for non-treatment, such a process to reduce errors is all the more arguable in these latter cases.

A second decision of importance to us is that of In the Matter of B, a 1981 English case.[475] It involved a baby born suffering from Down's syndrome and the intestinal blockage known as atresia The baby therefore required an operation to remove the obstruction if it was to live beyond several days. Her parents decided it would be kinder to allow her to die rather than live in a physically and mentally handicapped state. Their physician decided to respect the parents' wishes and not operate. The local child welfare association made the child a ward of the court and sought an order authorizing the operation. Whereas a lower court agreed with the parents and refused to make the order, the Court of Appeal overturned that decision and ruled that it was in the best interests of the baby to have the operation.

The court agreed that there was little doubt that the baby was severely mentally and physically handicapped, and acknowledged that the parents had the welfare of the baby in mind in refusing their consent. But it also noted that the evidence could not establish whether the child would suffer or how unhappy she would be, and she certainly would not be a "vegetable". The court expressed itself as follows:

> There may be cases, I know not, of severe proved damage where the future is so certain and when the life of the child is bound to be so full of pain and suffering that the court might be driven to a different conclusion, but in the present case the choice which lies before the court is this: whether to allow an operation to take place which may result in the child living for 20 or 30 years as a mongoloid or whether (and I think this must be brutally the result) to terminate the life of a mongoloid child because she also has an intestinal complaint. Faced with that choice, I have no doubt that it is the duty of this court to decide that the child must live.476

The court went on to add that the judge in the lower court decision gave too much weight to the wishes of the family:

> The judge was much affected by the reasons given by the parents and came to the conclusion that their wishes ought to be respected. In my judgment he erred in that the duty of the court is to decide whether it is in the interests of the child that an operation should take place. The evidence in this case only goes to show that if the operation takes place and is successful then the child may live the normal span of a mongoloid child with the handicaps and defects and life of a mongol child, and it is not for this court to say that life of that description ought to be extinguished.477

A third decision of interest is the 1983 Canadian case of Stephen Dawson.[478] It illustrates well the duty of physicians, the limits of parental authority and decision-making, the legal requirement to give first place to the interests of the child, and the relatively conservative interpretation courts tend to give to the child's interests. This case involved a petition by a child welfare agency to the British Columbia Supreme Court seeking authorization to repair a shunt which drained fluid from Stephen's brain. His parents had refused to consent to the operation.

Stephen had been born prematurely, and two weeks after birth contracted spinal meningitis while in the hospital, a bacterial disease which attacks the membranes of the spinal cord. He was left severely retarded and had a variety of related handicaps - especially cerebral palsy, hydrocephalus, blindness, almost total deafness, and incontinence. He had remained at home for only two of his six years, and for most of the remaining years he was in an institution for children with severe handicaps. In that institution he was cared for almost ten hours a day, including medication, feeding and physiotherapy. His parents, who admitted they had once contemplated killing Stephen, based their refusal of consent on their judgment that the contemplated operation was a life-saving one, and that in view of his serious disabilities Stephen had no future, would be better off dead and should be allowed to die "with dignity". A lower court had agreed with the parents and ruled that repairing the brain shunt would be a life-saving operation, that it would be an "extraordinary" surgical intervention given Stephen's condition, and that it constituted in these circumstances a "cruel and unusual punishment".[479]

But on appeal to the Supreme Court of British Columbia that decision was overturned and the operation was authorized. Several factors contributed to that decision. First of all, the testimony of the medical and nursing staff at the institution was given more weight than it had by the lower court. The judge noted that the parents had hardly seen

Stephen at all for four of his six years and that the staff of the institution was in a much better position to evaluate his condition and future prospects. The medical and rehabilitative staff testified that Stephen could lead a relatively normal life within the limits of his handicaps, that he did respond to stimuli and that he was improving or had the potential to improve.

A second factor insisted upon by the court was that the operation in question was not necessarily life-saving at all. Without it, Stephen might live indefinitely but in great and increasing pain. This was not therefore (concluded the court) a case of a terminally ill patient's right to die, because the medical condition was not necessarily life-threatening. It was rather about the right of a child to receive relatively routine medical care. The judge observed on this point:

> There is not a simple choice here of allowing the child to live or die according to whether the shunt is implanted or not. There looms the awful possibility that without the shunt the child will endure in a state of progressing disability and pain. It is too simplistic to say that the child should be allowed to die in peace.480

He concluded that the parents were wrong in thinking that Stephen will promptly die if treatment is denied, for it was not at all a certainty. The medical evidence in fact demonstrated the strong possibility that his life would go on indefinitely. He also emphasized that the professionals who had been treating and caring for Stephen were much better qualified to assess his condition and capacities than the parents who had hardly seen him over the past few years.

A third point made by the court is that at least in this case the standard of what the "reasonable person" would want done (accepted as a standard in Quinlan), is not applicable. The judge expresses the point this way:

> It is not appropriate for an external decision maker to apply his standards of what constitutes a livable life and exercise the right to impose death if that standard is not met in his estimation. The decision can only be made in the context of the disabled person viewing the worthwhileness of his life in its own context as a disabled person - and in that context he would not compare his life with that of a person enjoying normal advantages. He would know nothing of a normal person's life having never experienced it.481

Stephen Dawson is obviously too retarded to "view the worthwhileness of his life in its own context" in a reasoned or intellectual sense. But the implication of that observation by the court is that when others attempt to make treatment decisions for children (and infants) in conditions similar to Stephen Dawson, they should not assume that (relatively normal) lives and expectations can serve as the norm for what those seriously disabled infants would want. That might be acceptable in a Quinlan type case - the damage is clearer and given the irreversible coma the "worthwhile" life is over. It is hardly likely that Karen would have thought otherwise. But here in the case of Stephen, his condition is more ambiguous, and unlike Karen Quinlan, he never knew a normal existence. Normal existence is therefore not a useful or acceptable basis and standard by which to judge the best interests of one who never, or only partially, had it. And since we cannot know how such a child would view his own life, this judgment is rightly emphasizing in effect that we should err on the side of caution in making treatment decisions in cases involving similar facts.

The court concluded, fourthly, that only in the most extreme cases and in the best interests of the subject could a court ever condone withholding treatment. That conclusion is comprised of several elements. The fundamental premise is that: "the laws of our society are structured to preserve, protect and maintain human life and in the exercise of its inherent jurisdiction this court could not sanction the termination of life except for the most coercive reasons.

The presumption must be in favour of life."[482] The decision does not rule out the appropriateness of quality of life considerations per se, but they are suspect when to do so implies the disabled person does not "deserve" to live. Given the salvageable condition of Stephen, there is that implication here. Concludes the court: "I do not think that it lies within the prerogative of any parent or this court to look down upon a disadvantaged person and judge the quality of that person's life to be so low as not to be deserving of continuance".[483]

The Dawson court does not at all maintain that there are no circumstances in which withholding life-supporting treatment would be acceptable, and it quotes approvingly the circumstance already approved by the court in the earlier English decision of In the Matter of B referred to above, that is, "Where the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion". But given the facts of this case, the Dawson court chose to underline the fact that short of such extreme cases it is very difficult indeed to uphold a claim that death is preferable to life for those infants lacking full mental or physical abilities. The court therefore concludes that it cannot:

> accept their [the parents] view that Stephen would be better off dead. If it is to be decided that it is in the best interests of Stephen Dawson that his existence cease, then it must be decided that, for him, non-existence is the better alternative. This would mean regarding the life of a handicapped child as not only less valuable than the life of a normal child, but so much less valuable that it is not worth preserving. I tremble at contemplating the consequences if the lives of disabled persons are dependent upon such judgments.484

Though the values expressed and conclusion arrived at in the Dawson case undoubtedly represent the prevailing trend in such circumstances, there are exceptions. One such was the earlier American decision of In the Matter of Phillip B, a 1979 California decision.[485] Though not a case involving a newborn, the considerations and conclusions are directly relevant to the newborn context as well. Phillip was a mildly retarded twelve year old boy with Down's syndrome. He could communicate verbally and was educable, could dress himself, was toilet trained, had good motor and manual skills, and took part in school and Boy Scout activities. Phillip had been institutionalized since birth, at State expense. At the age of twelve he was found to have a cardiac defect, which, if repaired would ensure a normal life span, but if not repaired his heart would slowly deteriorate, he would suffer increasing distress and his dying would be prolonged and increasingly painful. Though Phillip had never lived at home, his parents refused consent for the operation. The institution brought a petition to court, alleging that his parents were denying him the necessities of life. The parents offered as their primary reason for refusing consent that they did not want Phillip to outlive them. They felt the geriatric care available in the United States was very inadequate and that he would not be well cared for after they died. As well, they did not wish him to be a burden on the other children in the family.

In the medical testimony, one of the pediatric cardiologists recommended the corrective surgery, placing the risk of death at 3 to 5 percent, which in his view was a low risk. There was also a 1 percent chance in his view that a heartblock might necessitate a pacemaker as a result of the surgery. The other pediatric cardiologist who testified said he probably would have recommended surgery if Phillip had been "normal", but did not commit himself as to whether it should be done for Phillip. He put the risks of death from surgery at 5 to 10 percent.

The lower court sided with the parents and did not order the surgery. The judge held that the surgery in the circumstances would be extraordinary or "elective", and it was not a "life-saving emergency". He referred to the inherent risks of surgery and praised the parents for their love and thoughtfulness. He added as well that if he had had a Down's syndrome child himself, he did not think he could handle it. His conclusion was that the parents' decision was in the "range of debatable actions", and that governments should be very hesitant to interfere with parental choices. The case was appealed, but the California Court of Appeal concluded that the lower court decision was correct and did not order the surgery. The only reason that Court gave for its decision was that there was a higher than average risk of morbidity if the operation should be done, and because the risk of surgery outweighed its benefits it need not be done. The Supreme Court was then requested to review the case, but declined to do so.

This judgment was widely criticized in legal and ethical analyses and in the public media, and in view of its radical departure from precedent and many fundamental flaws, it is most unlikely to be used as a precedent in subsequent decisions. In effect this decision stands for the quite untenable proposition that one need not treat Down's syndrome children. One legal writer (George Annas) convincingly suggests three factors which allowed that court to so conclude.[486] First of all, the lower court nowhere provides any articulated standard for the decision. In effect the closest it came to a standard, one which is totally inadequate, is that as long as parents sincerely believe in what they are doing courts should not "second guess" them. The appeals court did bow to the best interest standard, but if it had actually applied it, it could never have concluded as it did, that non-treatment is in Phillip's best interests. If no geriatric institutions provide adequate care, the parent's reason for not consenting to treatment, then the same argument would justify not treating any senior citizens. Secondly, the decision was made in a judicial vacuum, without any consideration of earlier cases which came to quite a different conclusion on the basis of carefully reasoned arguments. Treatment of Phillip would clearly have been ordered for example by the <u>Quinlan</u> court. Thirdly, the medical evidence was badly presented and weighed. A risk of death of 5 to 10 percent does not make the surgery extraordinary if one balances those risks against the certainty of prolonged debilitation and death by its non-provision.

One cannot escape the conclusion that this decision is a direct attack upon the mentally retarded and that behind both the parents' and the court's reasoning is the assumption that his life is really not worth living. Further evidence of that assumption is provided by a letter solicited by the parents from a pediatrician and introduced as evidence. The physician wrote that Phillip's life is devoid of "those qualities which give it human dignity", and that his simple and innocent nature makes him a nautral victim of people eager to take his money, and that he might not "fit into modern suburban society". As one commentator rightly observed:

> ... just when society is beginning to acknowledge an obligation to nurture the significant fulfillment of even the limited potentialities of retarded citizens, the Becker case works to cast those citizens into legal limbo as less than persons with a full right to life.487

C. Parental authority and the law

Earlier in this thesis (pp.224-226) it was suggested that there are essentially three theories of parental decision-making authority from which to choose. One is the "ownership" theory, according to which parents in effect own their children and have a right to make any decisions they wish affecting them, whether in the interests of those children or not. The second sees parents as "trustees" over their children, entitled to decision-making autonomy up to the point that their childrens' interests, especially their lives and health, are not endangered A third approach would hold that parents should not be involved at all, or only minimally, in life or death treatment decisions involving their children. We concluded, on the basis of surveys and other data that the choice in practice of very many pediatricians falls somewhere between the first ("ownership") and second ("trusteeship") options, though the third option also has many pediatrician adherents. In other words, most pediatricians and neonatologists give too much weight to parental wishes, even to the point of acquiescing in their wishes not to have their salvageable children treated. In our view, as argued above, that position is quite out of step with our Judeo-Christian bioethical norms, and only the second of the three options is compatible with them.

That is equally so for the law. There is a strong presumption in the law that parents are the appropriate decision-makers for their infants and minor children. Parents have a wide-range of discretion in matters to do with their children, and both courts and legislation diligently uphold their rights and freedom in these matters. For example they have the authority to establish their family's values and goals, to be free from interference by state agencies, to choose their childrens' schools and (short of negligence or abuse) they are free to choose the food, health care and shelter they wish for their children. But at the same time, infants and minor children, as persons unable to protect or fend for themselves, come under what is called the <u>parens patriae</u> power of the State. What that means is that the

State may punish parents who neglect or inflict abuse upon their children, and also supervene parental decisions and choices which endanger the child's welfare before those decisions become operative.

Parental decision-making authority over their infants and children therefore stops short of failure to supply or consent to needed health care. Such a failure can result in criminal prosecution (as described above) or in judicial proceedings to have the child or infant found "in need of protection" under provincial child welfare laws.[488] In the latter case, those proceedings can be commenced at short notice and can be held for instance in hospitals. A scheme is provided whereby someone else is appointed to provide consent to treat a child whose life or health is at risk, and if there is indeed such risk, the court authorizes the treatment against parental objections. The law does indeed show great respect for parental claims that it is they who have the responsibility for their children's physical, moral and spiritual welfare, but they do not normally allow parental wishes or convictions (including religious convictions) to prevail in the face of the health needs of their child or infant.

The decisions examined above confirm both the court's respect for parental wishes and authority in these matters, but also the limits of that authority. The <u>Quinlan</u> court for example, on the one hand agreed with the request of the parents that life-support for Karen be stopped, but it agreed not simply because it was what the parents wanted. It agreed because given the condition and expected quality of life of Karen the request was held to be "reasonable" and in Karen's best interests. To be sure that the wish really was in her best interests, the court added a condition, namely that the decision be confirmed by a hospital committee. The <u>In Re B</u> court expressed great sympathy for the parents' wish that their Down's syndrome infant not be treated, even noting that in the court's opinion their refusal of consent was "not because of the difficulties which will be occasioned to them, but in the child's interest".[489] Nevertheless, it went on to decide that objectively speaking it was not at all established that denying their child treatment would be in its interests, and the court authorized it. The <u>Dawson</u> court as well gave detailed consideration to the parents' assessment of Stephen and their desire that he not be treated. But this court as well demonstrated that parents are not necessarily as qualified as health professionals to assess their child's medical condition and likely future, and that it was in Stephen's objectively assessed interests to receive the treatment. There is no doubt whatever that the Becker court was attentive and sympathetic to the parental refusal of consent, but as argued above, altogether too attentive, at the expense of Phillip. Missing in that decision was an objective assessment of Phillip's condition and a careful weighing by the court of his best interests. Because this was not done, that decision is clearly an exception to the general trend, and unlikely to be followed by other courts.

We endorsed a number of times in what precedes the separation of treatment considerations from custody considerations. As noted, some physicians do make that separation in their dealings with the parents of disabled infants, but many do not. What recommends that approach is that it helps to keep parental fears and worries about how they would cope with the care of such a handicapped child from unduly influencing the objective determination of that infant's best interests regarding treatment. Such a separation also weakens the position of many physicians and others who hold that the predicted parental burdens of caring for a seriously handicapped infant provides justifications for selecting the infant for non-treatment. We argued in effect that when parents for whatever reason find the prospect of caring for such a child to be overwhelming, there is a third choice available to those of letting the infant die or burdening unwilling parents with its care for life. That third option is to allow their child to be cared for by others.

That option and argument of course assumes that such a course of action is acceptable in the eyes of the law, and that suitable legal mechanisms to enable it are available. That is in fact the case. Several legal avenues are open to parents who decide they are unable or unwilling to take custody of and provide adequate care for their disabled child. In most jurisdictions, existing child welfare legislation provides not only for the involuntary removal (in extreme cases) of children found to be in need of protection, but also provides that parents may voluntarily consent to temporary or permanent, partial or total suspension of their parental responsibilities and rights regarding their children.

One possibility is <u>full and permanent termination</u> of parental responsibilities and rights over their child. It provides parents who want to give up their child, who truly do not want the child, with a means of doing so without having to abuse or neglect it (in which case it would be removed involuntarily). The voluntary termination of parental responsibilities and rights would be normally accomplished by a parental petition to a court, which would then provide a court order to that effect. The court would wish to ensure that the parental consent is informed and voluntary. Applied to the case of a seriously disabled and unwanted infant, the parents would normally explain at the hearing the reasons for finding the burdens of care excessive and wishing to terminate their relationship to that infant. The court would want to be convinced that such a termination would be in the interests of the infant, but given that the parents do not wish to take it home, it is difficult to see how it could be in the child's interest to force unwilling (and perhaps inadequate) parents to do so.

Once the parental relationship is legally terminated, the legal custody and guardianship of the infant would be transferred by the court to a child welfare agency. (The infant would also at any point afterwards be freed for adoption by another person willing and able to do so). The court would normally determine the new guardian for the infant on the basis of the particular needs of the infant and the available resources.

There are also degrees of assistance available to parents of seriously disabled infants, less permanent and total than full termination of responsibilities and rights. For example, they could have their child institutionalized, in which case the parental relationship would continue, though legal custody would be with the State. They could also agree to accept support services which would ease their burden and allow their child to continue living with them.

Ideally, at the time when parents are asked to consent to a needed life-saving treatment for their disabled but salvageable infant or child, they should be informed of two things. First of all that not to treat this child may not be a legally available option in this case - they and the physicians may be violating the law if they do not treat it. But secondly, they have the legal right to terminate their responsibilities and rights over the child if they choose not to consent to its treatment for whatever reason. Given an urgent need for a decision, they could presumably petition a court immediately and a hearing could be held very quickly.

It might be objected that parents who do opt for termination of rights and responsibilities would experience more guilt than if they had refused consent and the child had died. In this case they would live with the continuing awareness that their child which they refused continues to live and is being cared for by others. But as Robertson rightly wrote of that objection, "it requires a person to feel better about having killed someone than having kept him alive. In either case responsibilities and duties have not been fulfilled, and it is hard to see why the marginal guilt should be so much greater with the latter". He goes on to add, that:

> There are many compelling reasons parents are not acting immorally when they decide to terminate [the relationship] instead of withhold treatment. Most theories of moral duty do not require persons to shoulder burdens beyond their capacities, even if they are praised when they do so. If caring for the child is an overwhelming burden, one may be acting ethically in keeping the child alive by transferring those obligations which one partially shares as a taxpayer to the State.490

Chapter X: Conclusions - towards a model policy

We are now in a position to draw some final conclusions from the analyses which precede, as to the influence of (theological) bioethics on treatment policies, practices and attitudes. The format of these concluding observations will consist in large part of a number of propositions. In our view they not only articulate the priorities central to theological bioethics, but also should be acceptable to at least some versions of secular bioethics, and reflect as well the parameters and priorities of law. Each proposition will be followed by a brief explanation and a summary as to whether and how that position is reflected in the medical, ethical and legal policies and practices examined in this thesis. In effect these propositions will be a sort of re-statement in the form of a "model policy" of the bioethical tests outlined in Chapter VI and expanded upon throughout the thesis.

This "model policy" is by no means intended to be a comprehensive guide, complete in all details and able to stand on its own by itself. The only claim made for it is that its propositions arguably encompass the preoccupations and norms central to Judeo-Christian bioethics, that they are compatible with much of secular/humanistic bioethics, and that they are within the bounds of law. It is the influence and role played by those propositions or commitments which has been the subject of this thesis.

A. The influence to date of Judeo-Christian bioethics

We begin, however, with a general concluding observation, one which will be supported in what follows. It is this: the influence and role of the Judeo-Christian bioethics we have proposed as normative, has not for the most part been great, and the prospects for its influence on treatment policies and practices in the future are not bright. If we can consider the views, practices and formal policies selected and examined to be generally representative of the contemporary scene, then some orientations and positions central to Judeo-Christian perceptions, values and commitments play only a minor role and influence in decision-making. They tend in many instances to be submerged by quite other considerations and values. At best, the attitudes and policies examined are ambiguous or selective about substantive matters central to our theological bioethics. That is true not only as regards the attitudes and treatment policies of many pediatricians, but also those of many bioethicists, including interdisciplinary policies which seek to be ethical in orientation.

While we have encouraged efforts to formulate interdisciplinary treatment policies in and for contexts encompassing many values and cultures, and while we continue to hope that is possible, one is not encouraged by the products of such efforts to date. Our analyses have underlined a very real, seldom acknowledged and yet to be resolved dilemma in present-day policy making. On the one hand the highly personal treatment views and practices of any individual physician (e.g. Dr. Lorber) are no longer tolerable given the pluralist context and public policy dimension and implications of treatment decisions. On the other hand the interdisciplinary policy designed for a pluralist context (e.g. the Sonoma policy) appears to be by definition (and perhaps by necessity) so general and ambiguous in order to accommodate the wide variety of moral and medical assumptions that substantive moral content and guidance is minimal.

One is inclined to conclude that such efforts and policies will be likely to succeed in encompassing the (justified) preoccupations of <u>philosophical or secular</u> bioethics, that is, the concerns for fairness, justice, tolerance and the procedural mechanisms to promote them, but less likely to succeed in incorporating the priorities which should be peculiar to <u>theological</u> bioethics, namely substantive norms and commitments. If the Sonoma policy is any guide at all, it suggests that it is by no means an easy task to strike the right balance between on the one hand tolerance and procedural fairness, and on the other, clear and unambiguous norms establishing moral priorities, limits and duties for all infants, disabled or not. The level of generality and openness needed to achieve the former, seems in practice to defeat the achievement of the latter. It was not and is not within our mandate to solve that dilemma in this thesis, but hopefully our analyses have at least established or confirmed its existence and the need to grapple with it more effectively.

Another element within our concluding observation has to do with the influence of religious affiliation on treatment views and policies. The results of the surveys and polls examined above (pp.210-216) as to the influence of religion for or against the treatment of disabled newborns, were somewhat ambiguous. Some of the results did support the conclusion that religion influences pediatricians in their preferences for or against treatment. But it is not clear whether religious affiliation alone or religiosity (i.e. degree of commitment to one's religion) is the greater influence and more important predictor. One survey found that the <u>least</u> religious pediatric heart surgeons (of all religious affiliations) were most likely to say they would operate on damaged newborns (p.214). One survey found that religious activity rather than the specific religious affiliation was the predominant religious factor (p.212), but another concluded that religious activity is a less important influence than religiosity (p.215). As for the influence of religion relative to other factors, one survey concluded that cultural background has more influence on treatment practices than religious background.

What makes it difficult to determine the influence of religious affiliation on the three theological bioethicists whose policies we examined is that in many respects the churches of which they are members do not have a clearly identifiable, distinctive or coherent position on the treatment of seriously disabled infants. In fact most denominations or churches tolerate a fairly wide variety of viewpoints, and some have not directly addressed the specific issue of handicapped infants at all, either authoritatively or in the form of a "discussion paper".

Fletcher is an Episcopalian (Anglican) and Ramsey a Methodist, yet on this issue (as on others) Ramsey appears much closer to (traditional) Anglican theology than does Fletcher. On the other hand, the Anglican Church of

Canada has in fact recently addressed some of the moral issues involved, but the report is more in the nature of a discussion paper than a definitive church position, and in many respects it is open and wide enough to accommodate both Fletcher and Ramsey.[491] McCormick, as a Catholic theologian, does in most respects seem to be greatly influenced by Catholic moral principles and priorities, though as we argued, his "relational capacity" criterion is at least potentially a serious departure from Catholic medical ethics and a threat to the equal treatment of the mentally disabled. As for Jonsen, another Catholic theologian, whatever his own ethical position, the Sonoma policy to which he contributed the theological perspective is at best ambiguous about a number of positions fundamental to Catholic medical ethics.

It is difficult to escape the conclusion that the very <u>variety</u> of bioethical positions and policies, and their very different moral assumptions, priorities and normative systems dissipates and weakens the influence of bioethics on treatment policies. Not only do philosophical bioethicists differ from theological bioethicists in their moral priorities and methods, but as we noted there are wide differences between theologians themselves. But whether or not that is to be regretted, a result is that it is not helpful to ask only the general question, "Does this or that medical treatment policy reflect bioethical considerations?" One can almost always conclude that a medical view or policy does reflect <u>some</u> bioethical viewpoint since bioethicists span the whole range of stances from Fletcher's situationalism to Ramsey's deontological approach. Given that reality, this thesis has addressed a narrower question to all the policies, medical, ethical and legal, namely, what role is played by the specific Judeo-Christian perspective defined and defended in Part One of the thesis? The answer provided in the body of the thesis, and summarized below, is, in many respects only a minor role.

A last general remark and conclusion has to do with legal policies. The analysis of relevant decisions by courts, legislation and legal commentators leads to the conclusion that the law in many fundamental respects reflects very closely the positions of the Judeo-Christian bioethics we proposed as normative. The fundamental concern of the law is to protect human life, including that of disabled newborns. Parents and physicians have duties to provide the "necessaries of life". From the legal perspective treatment decisions must be in the interests of the child's rights to life and health, not the lesser interests of others. Parents do have decision-making authority, but not at the expense of their children. Treatment and custody decisions are distinct in the eyes of the law. On the other hand the law and legislation require clarification, particularly in the matter of when one may not be legally obliged to treat and maintain life. Courts do sometimes decide against the best interests of children (as in the case of In the Matter of Phillip B) but such decisions are most unlikely to constitute legal precedents.

B. Towards a model interdisciplinary policy

As indicated at the start of this chapter, we will now list eighteen propositions (in the form of a "model policy") which express the priorities of the theological bioethics serving as our norm in this thesis. They could also be compatible with (some) secular analyses, and reflect legal parameters and priorities. Each proposition will be followed by a brief explanation, including the extent to which that position has or has not influenced medical, ethical and legal attitudes, practices and formal policies.

1. *Disabled infants whether physically or mentally handicapped, or both, are persons with full legal and moral rights. As such, parents and physicians are morally and legally responsible for providing them with the necessaries of life including medical treatment, a duty which continues until or unless such treatment is determined to be useless.*

Comments

The first proposition incorporates both the theological and the legal commitments to the sanctity of each individual life. That commitment, central to both perspectives, grounds the moral and legal duty to protect all lives without discrimination, whether disabled or normal, as long as the treatment remains useful to the infant. As long as that duty persists, if death results from a failure to fulfill it, it would be a homicide by omission. Subsequent propositions will clarify what is meant by useless or non-beneficial treatment.

As indicated in the body of the thesis, some medical and ethical treatment policies imply simply by their tendency to apply different standards and criteria to normal and disabled infants, that the latter are not really persons in the full sense. The mentally disabled infant is particularly likely to be classified as less than a person and unjustly discriminated against.

2. *The treatment bias should be one in favour of life. Decisions not to treat should be seen as exceptional, placing a heavy burden of proof on those advocating non-treatment.*

Comments

This proposition, like the first, incorporates in another form the sanctity of life principle. It is meant to underline the theological conviction, one also defensible from a humanistic perspective, that given the sanctity or dignity of life, and the duty to protect it, decisions to support life or not should never be thought of as requiring the same burden of proof. Doubts about whether to treat or not should normally be resolved in favour of life.

This perception and emphasis does not stand out in some of the medical and ethical policies and practices examined earlier. For many, it is almost as if the bias should be in favour of non-treatment, as if the real moral duty in the case of disabilities is to allow (or hasten) death, not to save life.

3. *In treatment decisions affecting seriously disabled newborn infants, the decision should always be made in the best interests of the infant. Lesser interests of others or of society should not prevail over an infant's right to life.*

Comments

The infant's right to life is not a value on a par with lesser rights or interests of others, such as the burdens on parents, health care professionals or society. The latter constitute important considerations, but they are not equal in moral weight to a salvageable infant's right to life. As noted several times in the body of the thesis, both our Judeo-Christian bioethics[492] and the law[493] insist on this point.

> 4. *In the interest of fairness and equality between disabled infants, the same treatment standards and criteria should apply to all the infants in the care of a given hospital or unit. In the interest of fairness and equality between disabled and non-disabled infants, a life-saving treatment which would normally be provided to a non-disabled infant should normally be provided as well to a disabled infant, unless determined to be clearly or probably futile.*

Comments

This proposition assumes, first of all, that treatment criteria and standards should indeed be authoritatively formulated and made public. Since treatment decisions and standards have serious public implications, some authoritative body representative of the community, perhaps in the final analysis a legislature[494] or a national commission,[495] should at least establish the limits beyond which individual choices and preferences of parents and physicians should not be socially acceptable. The proposition also incorporates the concern for fairness and equality which served as one of our bioethical tests in this thesis.

Clearly, in view of the need for fairness and equality, it is unacceptable that infants with similar disabilities be saved or not saved depending upon the values and criteria of the particular physician caring for them. Yet as established in the body of the thesis, that is in fact the present state of affairs in many units and hospitals. An example is that of the Childrens' Hospital in Sheffield, England, in which both Doctors Lorber and Zachary practice. It would be difficult to imagine two treatment policies more fundamentally different than theirs. As well, the medical attitudes and policies examined demonstrated the tendency to deny to disabled infants, particularly those who are mentally retarded, corrective interventions more or less routine for normal children. An example is the preference of some physicians and parents not to correct the bowel obstructions in Down syndrome infants, though they would normally do so for otherwise normal infants.

5. *The infant's quality or condition of life is a legitimate and important treatment consideration, both for dying and not dying infants, if by quality of life is meant the infant's own medical conditions and capacities. A vitalist sanctity of life position which would exclude quality of life factors from treatment decisions cannot be supported by either Judeo-Christian or humanistic ethics. This quality of life criterion should exclude:*

   (a) qualities (such as relational capacity) which are inevitably vague, subjective and difficult or impossible to measure accurately, and therefore likely to result in unjust discrimination, and,

   (b) "social" quality of life factors such as prediction about burdens on others or about the availability of care and services during the child's life. The latter are important for purposes of custody and care decisions, but should not be decisive in decisions to treat or not.

<u>Comments</u>

This proposition incorporates a position defended in the thesis, namely that quality of life concerns need not be seen as threats to the sanctity of life as long as the notion of quality of life focuses on the infant's present and predictable medical condition and not on the burdens and benefits to others or on factors impossible to predict with any accuracy or objectivity.

As indicated above (pp.352-358 and note 402a), while relational potential is arguably the most fundamental characteristic of the human person, there are some serious obstacles to its use as a decisive criterion for or against the treatment of disabled infants. Both philosophical and theological argumentation have in our view compellingly demonstrated that the meaning and purpose of human personal life is largely defined by the ability to relate with others. To exclude that capacity as decisive in the case of infants (except for the extreme case of anencephaly) is not to question that view.

Its inadequacy is more at the operational than the definitional level. It is because relational capacity cannot (except in extreme cases) be measured with accuracy that it is inappropriate as a yardstick for or against treatment. Until we have determined biological symptoms by which to confirm the presence or absence of some degree of that capacity, its determination will be inaccurate and subjective, inviting unjust discrimination in treatment decisions made on that basis.

Another limitation of that criterion is that (except in extreme cases) the capacity for relationship in a disabled person is to at least some degree determined by the ability and readiness of other parties to initiate and encourage relations. Since the contribution of other people towards the development of an infant's limited innate ability to relate cannot be reasonably predicted at the start of life, this factor too argues against the use of relational capacity as a treatment criterion.

"Social" quality of life factors such as the availability of care and services during a child's life are of course crucially important for decisions about custody and care. But assuming that treatment and life-prolongation is judged to be medically useful and beneficial to that child, then predictions about the long range availability of care or burdens on the care providers, should not lead to decisions not to treat or prolong that life. The expression "quality of life" implies to some, "measuring up", "passing a test", or "earning the right to life". To some it therefore risks promoting inequality between persons possessing varying degrees of a particular ability. It may therefore be preferable to substitute for the expression "quality of life", a more neutral term such as "condition of life". The more specific conditions or qualities of life which could justify the non-treatment of a seriously disabled newborn are listed in proposition 10 below.

6. *To advocate the treatment of seriously disabled infants implies a commitment to advocate as well for the availability of adequate and humane specialized continuing care and rehabilitation services which will be needed by infants who are treated and saved rather than allowed to die. To advocate and develop neonatal care and treatment in isolation from continuing care and training opportunities for the survivors would be unjust and hypocritical. The provision of more and better continuing care should be advocated even if it involves a considerable burden to society and a re-allocating of societal priorities.*

Comments

This proposition acknowledges that while the availability of future care and rehabilitation should not be a decisive factor in treatment decisions, these considerations are nevertheless crucially important. It is unrealistic to see them as completely distinct, and hypocritical not to advocate for both treatment and continuing care at the same time.

To a very large extent the views and policies examined in the thesis ignored the question of continuing care, or simply assumed that what now exists in that regard is the most that can be expected. But from both the Judeo-Christian and humanistic perspectives society should be prepared to devote a much larger proportion of our resources to providing for these most disadvantaged of our fellow citizens.[496]

7. *Active treatment of disabled infants should be undertaken not only for life-saving purposes, but also (when indicated) to maintain or improve function in those disabled infants who cannot or may not survive. In such cases the treatment, including in some cases surgical operations, is not provided in order to add time to life, but life to the time remaining.*

Comments

This proposition incorporates the crucially important observation and practice of physicians such as Zachary and Freeman. As opposed to Lorber, their practice is to treat almost all the spina bifida infants in their care, not because they can save them all, but because at birth it is often too soon to know their prospects for sure, and those who will not survive despite treatment will at least be able to function better for their sometimes brief life span. As well, a certain number of infants do survive to live for years in reasonable comfort and with some mobility because they were treated early despite a poor prognosis at birth.

As noted in our examination of medical and ethical practices and policies, most physicians and ethicists do not include the maintenance or improvement of function reason as a purpose for active and early treatment along with that of life-saving. Lorber for instance gives this goal no attention at all, a fact which undoubtedly contributes to the relatively large number of infants he selects for non-treatment.

8. *The proper mandate of medicine is not to eliminate all suffering and guarantee happiness. Such a goal is beyond the competence of physicians and has no foundation at all in medicine or ethics. The goal of medicine is that of doing everything within its power to cure and comfort patients, but that power does not extend to killing them out of compassion.*

Comments

This proposition encompasses a primary moral rule implied in the sanctity of life principle, that against killing. As suggested in the thesis, the killing of infants (by act or omission) implies a view that the mandate of medicine is not just to try to cure diseases or at least to alleviate suffering, but to eliminate all suffering and disability even if it means killing the patient. Quite apart from the fact that that is not a proper reading of the goal of medicine, it is the most paternalistic of all gestures. Assuming that treatment for an infant is not futile, then to kill that infant by act or omission would be to remove from that child all opportunity to make its own free choice in the years to come, to develop its own talents and strengths. To kill the suffering infant to cure suffering is also to shortchange society of the challenge to respond to these infants with the sort of compassion which provides more care and rehabilitation, not a compassion which kills.

As noted in our examination of medical views, there is considerable sympathy among pediatricians (and some ethicists) for the killing of disabled infants. Though killing by act may not be frequent, killing by omission (e.g. over-sedation and starvation) appears to be frequent enough, and more or less implied in treatment policies such as Lorber's. The fact that so many physicians, for example Duff and Campbell, would like the legal prohibition against killing to be relaxed, indicates that the traditional Judeo-Christian prohibition against it may be decreasingly influential.

> 9. *Strict treatment criteria in the form of adverse physical criteria (e.g. those of Lorber) are legitimate and useful. But applied too rigidly, too early or too exclusively, they are inadequate and too likely to exclude some infants from treatment who should be treated.*

Comments

The physical criteria developed by Lorber as counterindications of treatment are useful towards that decision and for purposes of predicting the kind and degree of care likely to be necessary later. But the quality of life assumptions underlying the criteria are unduly pessimistic, and not as predictable as the criteria and their early application imply. To apply them on the first day as he does is to make no allowance for a number of factors which can lead to a different assessment of an infant's present and future medical condition, and to its improvement. It is too early to be able to predict on the first day, or even in the first days, the readiness and ability of parents to bring the child home and to compensate for the disabilities by their love and care, or the availability of needed rehabilitative services as the child grows. Strictly medical criteria and prognoses tend to ignore (or disguise) the value considerations at least implicitly involved in all treatment decisions.[497]

> 10. *Infants may never be killed by act or omission, but may be selected for non-life-saving treatment if:*
>
> *(a) the infant has an irreversibly life-threatening condition, and death is imminent, and no available therapeutic or life-saving treatment can do more than prolong for a short time the dying process, or,*
>
> *(b) the infant, whether irreversibly dying or not, has suffered such extensive brain damage that it would not be reasonable to think of this child having any interests at all, or,*
>
> *(c) the infant, whether irreversibly dying or not, has a condition causing extreme and irremediable pain and discomfort, or,*
>
> *(d) excessively burdensome qualities would be caused by or associated with the only means available to sustain the infant's life.*

Comments

These general criteria flow from and are consistent with the analyses in various parts of the thesis. As already indicated above, (in Chapter IX) they are arguably acceptable in the eyes of the law, given the legal judgments and analyses to date. They encompass in the form of criteria one of the basic principles defended in this thesis, that Judeo-Christian bioethics imposes a very restrictive meaning on the quality of life considerations which are legitimate in decisions not to provide or continue life-sustaining treatment. That means in effect the exclusion of criteria which focuses on capacities likely to be too vague to measure with objectivity, or too discriminatory given that they would encourage the assigning of more value to some persons than others. The above criteria also focus exclusively on the best interests of the infant, and exclude criteria which depend upon predicting the unpredictable (i.e. the availability of health services in the future), or upon a confusion of treatment and custody factors. In effect these criteria owe much to the "ordinary/extraordinary" means distinction, especially as regards the notion of "excessive burdens". These criteria are also particularly reflective of and compatible with the medical policy of Dr. Zachary examined above.

11. *In the interests of accuracy and fairness in treatment decisions, review committees should be established in hospitals.*

Comments

Given the need to exclude as much as humanly possible the risk that infants who should be treated are not excluded from treatment, there is a need both for carefully articulated criteria and appropriate review of a proposed course of action, especially for uses in which the infant's prognosis is uncertain, or the parents and physicians do not agree about whether to treat or not. Decisions by courts are sometimes necessary in these cases, but given the public and adversarial element involved in decisions by courts, they should be resorted to in the last instance, not the first.

The existence of such committees has been widely endorsed,[498] and could be an important educational and consultative resource which serves a number of purposes. Four purposes which have been proposed are these: to verify that the best information is being used; to confirm the propriety of a decision reached by parents and physicians in order to ensure that it does not exceed parental discretion from ethical and legal points of view; to resolve disputes by improving communication and understanding; to refer cases to public agencies (child protection services, or judicial authorities) if appropriate.[499] A related advantage of such committees is that they could provide a forum in which the participants would develop experience in discussing and resolving ethical problems and dilemmas. As such they may perhaps be able to supply a policy's specifics on a case by case basis which are difficult to incorporate into a general treatment policy.

It is worth noting that most of the medical and ethical treatment views and policies examined paid no attention to this important procedural factor. Due to space limitations we too did not explicitly address the subject of such committees, though support for such a procedure is at least implicit in the analyses and conclusions of this thesis. We do not at all agree with those who state or imply, as does Ramsey, that procedural matters are necessarily quite secondary and more or less unrelated to substantive matters.[500] Insofar as review committees could be an important step towards ensuring more accuracy and less risk of mistakes, they are directly related to the substantive matter of better protecting the right to life of the disabled newborn.

12. *Parents do not own their children, but are their trustees. Therefore they do have decision-making authority over them, but it has its limits. They cannot enforce decisions which endanger the lives of a salvageable infant, but they do have a right to be fully informed about the condition of their child in order to make fully informed decisions.*

Comments

This proposition incorporates what we have argued is the ethically and legally defensible view of the parameters of parental authority. As demonstrated in the body of the thesis, parents have obligations to provide necessaries of life including medical treatment, and physicians are not relieved of their own obligations to do the same only because parents give them permission.

Up to the point of endangering the lives or health of their children, however, parents do have the right to make decisions affecting them. That being so, they should be fully informed about the condition and prognosis of their child, though of course in the most sensitive manner possible. As suggested above (pp.228-230), the arguments usually made in defence of keeping parents more or less in the dark are not convincing, that is, arguments based upon parental guilt and anxieties, or the alleged inability of parents in this position to make objective decisions.

13. *Physicians should inform themselves, and parents of a disabled infant should be informed, of all the realities and prospects to do with disabled children, both the positive and negative aspects. Every effort should be made to correct misconceptions about both the mentally and physically handicapped child.*

Comments

The readiness of so many physicians to acquiesce with parental wishes not to treat disabled but salvageable infants, and some of the physicians' views about mentally handicapped infants referred to in the thesis, indicate much ignorance and undue pessimism about the burden of these children to others, their prospects for a reasonable amount of happiness, and the availability of remedial and rehabilitative services. Parents as well often share these same misconceptions. Without downplaying the difficulties and burdens, there is often a more positive and hopeful side as well which should be weighed in coming to treatment decisions. The myths and fantasies, especially about mental handicaps, exert a powerful pressure to allow or hasten the death of these infants.[501] Unless corrected and balanced they contribute to the unjust deaths of many of these children.

14. *The decision about whether to treat or not should be kept distinct from considerations about custody and care. If treatment is determined to be clearly beneficial, but the parents refuse consent, they should be informed that,*

   (a) they and the physician may be acting illegally if they do not treat, and,

   (b) they have the right to have their child institutionalized, or to have their rights and responsibilities over their child terminated.

Comments

Our examination of the treatment policies of physicians and ethicists revealed that many decisions not to treat disabled infants are based not so much upon whether or not treatment would be beneficial but upon the burdens of care upon others. What has happened in effect is that treatment and custody considerations have been fused. This proposition urges that they be separated, and that parents be advised that there are alternatives to those of either treating against parental wishes or non-treatment. These alternatives are especially those of institutionalization or termination of parental rights and responsibilities. As for non-treatment when clearly beneficial (confirmed if necessary by a review committee or a court), the legal perspective should not be overlooked as it appears to be by many physicians and parents. For physicians to comply with parents in this case may well be against the law.

15. *If parents continue to refuse their consent to treatment believed by the physician to be clearly beneficial, assuming they do not wish to have their rights and responsibilities over their child terminated, then,*

    (a) the case should be referred to the hospital or neonatal unit review committee, or,

    (b) if that does not result in a decision consistent with that child's best interests, a court should be requested to rule on it.

Comments

This and the next two propositions were suggested by the Report of the President's Commission, in which there is a distinction made between therapies which are clearly beneficial, clearly futile, and ambiguous.[502] Those distinctions provide a useful framework for relating the variety of possible prognoses to the variety of parental wishes. In general terms, "clearly beneficial" treatment would be those which clearly cannot fit within the exceptions provided for in proposition No.10 above.

This and some other of these propositions assume that physicians will sometimes be called upon to play the role of "infant advocate". That role, discussed at some length above (pp.231-236), is not at all a paternalistic one towards parents or newborns. Rather it is exercised to protect infants from parents who may be inclined to exceed their moral or legal authority by a choice which unjustly places their child's health or life at risk.

16. *When it is difficult to determine whether treatment would be beneficial or not, if parents wish it to be provided, it should be provided, if they do not, it could be omitted.*

Comments

There are some cases in which it is difficult to determine whether treatment will be beneficial or not,[503] though the longer some infants survive the clearer will be the picture as to whether or not active treatment will be useful. Assuming that the picture remains unclear it should be the prerogative of parents to make the decision. As already indicated, their decision should only be challenged and countered when that decision is determined to be against the infant's best interests, but that is not clear in these cases.

17. *When it is clear that no available treatment will be beneficial to an infant and the parents nevertheless wish it to be provided, it should be provided as long as it will not cause the infant additional and severe distress. Should treating physicians not wish to provide what they rightly view as useless treatment, they should be free to withdraw from the case.*

Comments

Many clearly futile therapies will in fact cause additional and severe distress to infants, and neither parents nor physicians should be free to insist upon them. To do so would be a form of abuse, both ethically and in the eyes of the law. But if no severe added distress to the infant is caused, providing it despite its futility is justified out of deference to parental wishes. They may not yet be ready to abandon hope, and may need more time to adapt to the futility of further therapeutic treatment.

> 18. *Even after a decision not to treat therapeutically, physicians and parents have a duty to continue providing care and comfort to the infant. That duty will not normally include intravenous feeding when death is imminent and unavoidable. To do so merely prolongs the dying process.*

Comments

This proposition encompasses on the one hand the duty insisted upon by Ramsey and others, that the provision of care and comfort should continue until death, whatever the decision about therapeutic treatment. That duty was underlined many times in this thesis, and is founded upon the respect owed to each individual life, no matter how weak or what its prospects.

The matter of intravenous feeding is a particularly difficult one. To resolve its applicability one should begin by noting that the particular tasks which fall within this duty are not unlimited, but are conditioned by the infant's condition. While it is morally and legally wrong to cause death by starvation, the non-provision of intravenous feeding should not be construed as doing so when an infant is facing imminent and unavoidable death. In this case intravenous feeding is more in the nature of a prolonging of death which is being caused by the disease. To insist upon such feeding for example of an anencephalic newborn, would be a futile gesture. Death is imminent and further such treatment futile. To insist that nutrition and fluids must be provided to <u>every</u> infant, no matter how desperate the condition (as was recently done),[504] will in many cases not benefit the infant whatsoever and may well cause additional grief to the infant's parents.

REFERENCES

1. R.S. Duff and A.G.M. Campbell, "Moral and Ethical Dilemmas in the Special Care Nursery", (1973) 289 New England Journal of Medicine, 890.

2. See infra., pp.223-236.

3. Some institutions and physicians are relatively aggressive in deciding in favour of treatment of disabled newborns, whatever the parental wishes. An example is reported to be the Children's Hospital of Philadelphia. See, D.C. Drake, "Keeping Infants Alive is Only Half the Battle", Philadelphia Inquirer, September 24, 1978, 16.

4. See infra., pp.254-284.

5. See infra., pp.215-223.

6. See for example Diana Crane, The Sanctity of Social Life: Physicians' Treatment of Critically Ill Patients, Russell Sage Foundation, New York, 1975. On the basis of her survey of physicians she notes the following on this point:

   > The pediatric heart surgeons were presented with case histories of salvageable patients only. They were much less likely to say that they would perform cardiac surgery upon children with an accompanying severe, but treatable mental anomaly, mongolism, than upon children with an accompanying severe, but treatable physical anomaly... The interviews suggested that the medical standards which are applied to mentally retarded children are different from those which are applied to normal children. (pp.45-46).

7. See infra., pp. 390, 391, 400-404.

8. See infra., pp. 171-172, 215-223.

9. Freeman, John M., "Ethics and the Decision Making Process for Defective Children", in, David J. Roy, (ed.), Medical Wisdom and Ethics in the Treatment of Severely Defective Newborn and Young Children, Eden Press, Montreal, 1978, at p.36.

10. See Albert R. Jonsen and Michael J. Garland (eds.), Ethics of Newborn Intensive Care, Institute of Governmental Studies, U. of California, Berkeley, California, 1976, at p.188. It should be emphasized on the other hand that surveys of physician attitudes and practices consistently indicate no real support for active euthanasia. As Diana Crane observed (op. cit., supra, n.6, at p.200):

> ... there appears to be a very strongly held norm in the medical profession against direct killing, even when the individual has no capacity whatsoever to develop social relationships. Only a handful of pediatricians said that they would be likely to kill an anencephalic infant.

11. That at least is a point made by Dr. R.B. Zachary in criticism of the selective non-treatment practices of some clinics in the U.K. See, R.B. Zachary, "Life With Spina Bifida", (1977) 2 British Medical Journal, 1460. After noting that some of these babies received very poor care and that some received 60 mg/kg body weight of chloral hydrate four times a day, he adds, "No wonder these babies are sleepy and demand no feed, and with this regimen most of them will die within a few weeks, many within the first week". (p.1461).

12. Judicial Council of the American Medical Association, Current Opinions, American Medical Association, Chicago, 1982, at p.9.

13. Ramsey, Paul, Ethics at the Edges of Life, Yale U. Press, New Haven, 1978, at p.xv.

14. Ramsey, Paul, "The Nature of Medical Ethics", in, Stanley Joel Reiser, Arthur J. Dyck, William J. Curran (editors), Ethics in Medicine, Historical Perspectives and Contemporary Concerns, The MIT Press, Cambridge, Mass., 1977, 123, at p.124.

15. Ibid.

16. Id., at p.123.

17. Jonsen, Albert R. and Hellegers, André E., "Conceptual Foundations for an Ethics of Medical Care", in, S.J. Reiser, et al., (eds.), op. cit., supra, n.14, at p.129.

18. Callahan, Daniel, "Bioethics As A Discipline", in, James M. Humber and Robert F. Almeder, Biomedical Ethics and the Law, Plenum Press, New York, 1976, 1, at p.4.

19. *Ibid*.

20. Ramsey, P., *op. cit.*, *supra*, n.14.

21. Callahan, D., *op. cit.*, *supra*, n.18, at p.8.

22. *Ibid*.

23. A recent acknowledgement of this achievement by a physician, is that of Robert S. Morrison, "Bioethics After Two Decades", (1981) 11:2 Hastings Center Report, 8. He observes, "The greatest achievement so far may be methodological. Current biomedical ethics has shown the academy that interdisciplinary scholarship really is possible." (p.9).

24. *Ibid*.

The threat to interdisciplinarity from over-professionalizing has also been noted by some bioethicists, but by no means all are alert to the danger. One who is is Peter Steinfels who (with a touch of humour rare in the field) notes the following:

> Legal scholars and social scientists and medical clinicians and biological researchers may be left sitting around the edges making marginal comments while the "bioethicists" discuss why utilitarians are all right in the sprints but deontologists better for distance. The interdisciplinary character of bioethics would quickly disappear as first philosophy, then other disciplines (medicine, sociology of medicine, law), tried to get a corner on the market.
>
> "Against Bioethicists", (1976) 6:2 Hastings Center Report, 18, at p.19.

25. Morrison, Robert S., *op. cit.*, *supra*, n.23, at p.10.

26. Annas, George J., "Medical Remedies and Human Rights: Why Civil Rights Lawyers Must Become Involved in Decision-Making", (1972) 2:2 Human Rights, 151, at p.165.

27. See for example Edmund Pellegrino, Humanism and the Physician, U. of Tenn. Press, Knoxville, 1979, who writes of that influence:

> The good physician is by the nature of his vocation called to practice his art with high moral sensitivity. For two millennia this sensitivity has been provided by the oath and the other ethical writings of the Hippocratic Corpus. No code has been more influential in heightening the moral reflexes of ordinary men. Every subsequent medical code is essentially a footnote to the Hippocratic precepts, which even to this day remain the paradigm of how the good physician should behave. (p.95).

As an instance of the continuing respect paid in medicine to the Hippocratic Oath, the Code of Ethics of the Canadian Medical Association contains the following:

> A physician should be aware of the traditional standards established by his forebears and act within the general principles which have governed their conduct. The Oath of Hippocrates represented the desire of the members of his day to establish for themselves standards of conduct in living and in the practice of their art. Since then the principles established have been retained as our basic guidelines for ethical living with the profession of medicine.

Canadian Medical Association, Code of Ethics, approved by the General Council, 1982.

28. See, Ludwig Edelstein, "The Genuine Works of Hippocrates", in, Ancient Medicine: Selected Papers of Ludwig Edelstein, Johns Hopkins U. Press, Baltimore, 1967, 133-44; Pellegrino, Edmund D., "Toward an Expanded Medical Ethics: The Hippocratic Ethic Revisited", in, Roger J. Bulger (editor), Hippocrates Revisited, Medcom Press, New York, 1973; Jonsen, Albert R., "Do No Harm: Axiom of Medical Ethics", in, Stuart Spicker and H.T. Engelhardt (editors), Philosophical Medical Ethics: Its Nature and Significance, D. Reidel Pub. Co., Boston, 1977, 27-41; Robert Veatch, A Theory of Medical Ethics, Basic Books Inc., New York, 15-26, 141-169.

29. Hippocrates, "Oath", p. 120. The English translation referred to here is that of W.H.S. Jones, Hippocrates, The Loeb Classical Library, Harvard U. Press, Cambridge, vol. 1, 1923. Page references here and elsewhere are to that translation and publication.

30. Hippocrates, "Precepts", VI, Jones, (trans.) p.125.

31. Hippocrates, "Epidemics", Jones, (trans.). p.163.

32. Hippocrates, "The Art", Jones, (trans.) p.194.

33. Hippocrates, "The Art", Jones, (trans.) p.195.

34. Jonsen, Albert R., "Do No Harm: Axiom of Medical Ethics", in, Stuart F. Spicker and H.T. Engelhardt (editors), Philosophical Medical Ethics: Its Nature and Significance, D. Reidel Pub. Co., Boston, 1977, 27 at p. 40.

35. The philosopher bioethicist is H.T. Engelhardt, for instance in his, "Aiding the Death of Young Children", in, M. Kohl (ed.), Beneficent Euthanasia, Prometheus Books, Buffalo, 1975. The theologian ethicist is Richard McCormick, for instance in his, "To Save or Let Die", in, How Brave a New World?, Doubleday, Garden City, N.Y., 1981.

36. Jonsen, Albert R. & Hellegers, André E., op. cit, supra n. 17 at p. 132.

37. This aspect is documented by Ludwig Edelstein, undoubtedly the leading interpreter of the Hippocratic Corpus. See, L. Edelstein, Ancient Medicine: Selected Papers of Ludwig Edelstein, Johns Hopkins University Press, Baltimore, 1967.

38. It should be noted that modern revisions of the Hippocratic Code do generally affirm (at least briefly) patient autonomy. For example the CMA Code of Ethics (approved 1982) states under the heading of patient's rights: "An ethical physician will recognize that the patient has the right to accept or reject any physician and any medical care recommended to him." That autonomy is also implicit in the CMA Code's assertion that, "An ethical physician will, when the patient is unable, and an agent unavailable, to give consent, render such therapy as he believes to be in the patient's interest."

39. Hippocrates, "Decorum", XVI, op. cit., supra, n.29, at p.43.

40. Ibid.

41. Canadian Medical Association, Code of Ethics, approved by the General Council, 1982.

42. Bok, Sissela, "The Tools of Bioethics", in S.J. Reiser and A.J. Dyck, op. cit., supra n. 14, 137 at p.139.

43. Hippocrates, "Precepts", op. cit., supra n. 29 at p.126.

44. Canadian Medical Association, Code of Ethics, approved by the General Council, 1982.

45. Considerably more eloquent and explicit than either the Hippocratic Corpus or recent descendents in the form of present-day medical codes, are some medical canons of other civilizations in antiquity. Consider for example the following from a Chinese medical canon from between 200 B.C. and 200 A.D. (provided by S. Bok, op. cit., supra n. 42 at p. 138):

> He should have bowels of mercy on the sick and pledge himself to relieve suffering among all classes. Aristocrat or Commoner, poor or rich, aged or young, beautiful or ugly, enemy or friend, native or foreigner, and educated or uneducated, all are to be treated equally. He should look upon the misery of the patient as if it were his own.

46. Canadian Medical Association, Code of Ethics, approved by the General Council, 1982.

47. See, W.H.S. Jones, The Doctor's Oath: An Essay in the History of Medicine, Cambridge U. Press, 1924, p. 23.

48. See for instance, Edelstein, op. cit., supra n. 37 at pp. 174-175; Robert Veatch, A Theory of Medical Ethics, Basic Books Inc., New York, 1981, p. 24.

49. See, Reiser, Dyck & Curran op. cit., supra n. 14, pp. 10-16.

50. For example, the following leaders in that field are all rabbis: David Bleich, David Feldman, Immanuel Jacobovits, Seymour Siegel, Moses Tendler.

51. This was especially so in the medieval period, Moses Maimonides himself being also a physician. See, Immanuel Jacobovits, "Judaism", in Warren T. Reich (ed.), Encyclopedia of Bioethics, vol. 2, The Free Press, New York, 1978, 791-802. A modern example of combining in one person a physician and rabbinic scholar writing in the area of medical ethics, is Fred Rosner.

52. These are among the main principles identified as such by Jacobovits, op. cit., supra n. 51, 792. Others listed by him are: a rejection of superstition in healing, strict dietary restraints and instructions on the rights of the dead. See also his, Jewish Medical Ethics: A Comparative Study of the Jewish religions, Bloch Pub. Co., New York, 1962.

53. Quoted by David Bleich, in, "Theological Considerations in the Case of Defective Newborns", in, Chester A. Swinyard (ed.), Decision Making and the Defective Newborn, Charles C. Thomas, Springfield, Ill., 1978, 512, at p.531. See also his, "The Obligation to Heal in the Judaic Tradition. A Computative Analysis", in, Fred Rosner and J. David Bleich, (editors), Jewish Bioethics, Sanhedrin Press, New York, 1979, 2, at p.17.

54. See regarding these points, Bleich, Id., pp.531-534.

55. Moshe Tendler, as quoted by Howard Brody in, Ethical Discussions in Medicine, Little, Brown & Co., Boston, 1976 at p.66. A similar Jewish view is the following by Byron Sherwin in, Marvin Kohl (ed.), Beneficient Euthanasia, Promethus Books, N.Y. 1975:

> According to Jewish law, life is to be preserved, even at great cost. Each moment of human life is considered intrinsically sacred. Preserving life supersedes the "good life". The sacredness of life and the uniqueness of the individual require that every possible action be taken to preserve life. (p.7).

56. The biblical authority allowing the physician to heal a sick person is based in rabbinic teaching upon Ex. 21:19-20.

57. See Bleich, op. cit., supra n. 53, pp.535-537.

58. Rosner, Fred, "The Jewish Attitude Toward Euthanasia", in Fred Rosner and J. David Bleich (editors), Jewish Bioethics, Sanhedrin Press, New York, 1979, 253 at p. 262.

59. See, Jacobovits, Jewish Medical Ethics, op. cit., supra n.52.

60. See, Bleich, Theological Considerations, op. cit., supra, n. 53, pp. 552-553.

61. Among these writers were: Alphonsus Bonnar (in the U.K.), Edwin Healy, Gerald Kelly, and Thomas O'Donnell (in the U.S.), Albert Niedermeyer (in Germany), P.G. Payen (in France) and Luigi Scremin (in Italy).

62. The historical development of Roman Catholic Medical ethics was traced by Charles E. Curran in, Transition and Tradition in Moral Theology, U. of Notre Dame Press, Notre Dame, 1979, 176-184.

63. Summa Summarum, 4 vols., Vincentius de Portonariis, Lyons, 1542.

64. Curran observes that whereas in the first millenium of Christianity it was not unusual for clerics to be also medical doctors, they were subsequently prohibited to practice medicine apparently due to many devoting their full time to medicine. The prohibition still exists in the Code of Canon Law, but exceptions can be made in cases of necessity or for good reasons.

65. One of the most influential of those writing about pastoral medicine in the late nineteenth century was the German physician Carl Capellmann. Other important contributors were André Eschbach and Joseph Antonelli.

66. Curran, Charles E., op. cit., supra n. 62 at p. 185.

67. Thomas Aquinas, Summa Theologica I-II, Q. 94 art. 2.

68. For example Gerald Kelly, Medico-Moral Problems, Catholic Hospital Association, St. Louis, 1958, pp. 19-20.

69. See, Richard McCormick, "The Judeo-Christian Tradition and Bioethical Codes", in his, How Brave a New World, Doubleday, Garden City, N.Y. 1981, 3-17.

70. Id., at p.9.

71. Curran, Charles, op. cit., supra, n. 62 at p.187.

72. This submission of intellect and will to authoritative teaching by the pope was insisted upon as recently as the Second Vatican Council, in The Constitution on the Church, n. 25.

73. Vaux, Kenneth, Biomedical Ethics, Harper & Row, New York, 1974, at p.16.

74. Curran, Charles, op. cit., supra, n. 62 at p.202.

75. There are however several contemporary Roman Catholic bioethicists who maintain that in some circumstances active euthanasia should be allowed. One such is Daniel Maguire. See his, Death by Choice, Schocken Books, New York, 1975.

76. A somewhat extreme expression of that fear is the following:

> 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 killing.

Donald De Marco, Catholic Register, Jan. 23, 1978.

77. McCormick, Richard, "To Save or Let Die: The Dilemma of Modern Medicine", in How Brave a New World, Doubleday, Garden City, N.Y. 1981, (originally published 1974), at p.345.

78. Theological support for this mandate to intervene (responsibly) in nature, for this shared dominion over creation, extending even to life and death decision-making, can be found in the Catholic context in what is referred to as incarnational theology, or as the "theology of the world". It is not an exclusively Catholic theology by any means, and there are parallels in the Protestant context as well in what has come to be called "secular theology". The "founder" of this theological perception in modern times was in fact the Protestant theologian, Dietrich Bonhoeffer who made it a central theme of his writings that it was the design

of God that men manage their lives without him - he remains present to us but does not intervene to make our decisions for us. Other Protestants in this "school" are Harvey Cox, Rudolf Bultmann, W. Pannenberg and Friedrich Gogarten. In the Roman Catholic context the leading proponent and interpreter of this theological/biblical perception is Johannes Metz. He wrote (in Theology of the World, Seaburg Press, New York, 1973) that our times are characterized by a transition from a "divinized" to a "hominized" world, and this is in accord with God's plan. The world is as yet largely unformed and rough-hewn material, requiring to be continually shaped by man's free creativity. Other Catholic theologians in this stream are Karl Rahner, Gustave Thils and Teilhard de Chardin.

79. For more on these implications, see for example Richard McCormick, op. cit., supra, n.69, pp.12-14.

80. Smith, John E., "Panel Discussion: Moral Issues in Clinical Research", (1964) 36 Yale Journal of Biology and Medicine, at p.463.

81. Barth, Karl, Church Dogmatics, Vol. 3, Part 4, T. & T. Clark, Edinburgh, 1761, at p.339.

82. Thielicke, Helmut, The Ethics of Sex, Harper & Row, New York, 1964, at p.81.

83. Ramsey, Paul, "The Morality of Abortion", in, John Rachels (editor), Moral Problems: A Collection of Philosophical Essays, Harper & Row, New York, 1971, at p.11.

84. Ramsey, Paul, The Patient As Person, Yale University Press, New Haven, 1970, p.155.

85. Barth, Karl, op. cit., supra, n.81, at p.425.

86. Ramsey, Paul, op. cit., supra, n.84, at p.151.

87. Id., at p.150.

88. Id., at p.161.

89. Ibid.

90. Id., at p.163.

91. Id., at p.164.

92. Although Ramsey does then add a further caution in the form of a reminder that the aberrations of Nazi medicine started with small beginnings In this regard he quotes (at p.164) Leo Alexander ("Medical Science Under Dictatorship", (1949) 241 New England Journal of Medicine 44, at p.45):

> Whatever proportion these crimes finally assumed, it became evident to all who investigated them that they had started from small beginnings... It started with the acceptance of the attitude . . that there is such a thing as life not worthy to be lived .. its impetus was the attitude toward the non-rehabilitable sick.

93. Fletcher, Joseph, "The Right to Live and the Right to Die", (1974) 34:4 The Humanist, at p.12.

94. Id., at p.12.

95. Id., at p.13

96. Ibid.

97 Fletcher, Joseph, "Indicators of Humanhood: A Tentative Profile of Man", (1972) 2:5 Hastings Center Report 1.

98. Fletcher, Joseph, "Four Indicators of Humanhood - The Enquiry Matures", (1974) 4 6 Hastings Center Report 4.

99. Bard, Bernard. and Fletcher, Joseph, "The Right to Die", Atlantic Monthly, April, 1968, at p.64.

100. Fletcher, Joseph, op. cit., n.97, at p.1.

101. Ramsey, Paul, op cit., supra, n.13, at p.203.

In Chapter VIII we will evaluate in some detail the reasons why Ramsey disapproves the use of quality of life criteria, and prefers a "medical indications" policy.

102. Id., at p.204.

103. Ramsey argues compellingly that Fletcher and others are wrong and confusing to refer to decisions to only care for the dying, or to allow a patient to die with care, as "indirect euthanasia". He argues that the term "euthanasia", without qualifiers, should be restricted to its common meaning - direct killing.

104. Fletcher, Joseph, "Ethics and Euthanasia", (1973) 73 American Journal of Nursing, 670 at p.673. For Fletcher's views on euthanasia see also, Bernard Bard and Joseph Fletcher, op. cit., supra, n. 99 at p.63; "Euthanasia and Anti-Dysthanasia", ch. 9 of his Moral Responsibility, Westminster Press, Philadelphia, 1967, pp. 141-160.

105. Gustafson, James M., "The Contributions of Theology to Medical Ethics", (1976) Perspectives in Biology and Medicine, 247 at p.257.

106. Ibid.

107. Id., at p.258.

108. Ibid.

109. Id. at p.259.

110. Ramsey, Paul, op. cit., supra n. 84 at p.xiv.

111. In Barth's theology for example, creation itself is an aspect of covenant: "the covenent is the internal ground of creation ... creation ... the external ground of the covenent." See Karl Barth, Church Dogmatics, Vol. 3, Part 2, T. & T. Clark, Edinburgh, 1961 at p.

112. In his, The Patient as Person, (op.cit., supra, n.84) for example Ramsey states: "I hold with Karl Barth true covenent-fidelity is the inner meaning and purpose of our creation as human beings, while the whole of creation is the external basis and condition of the possibility of covenent." (p. xii).

113. Ibid.

114. Ibid.

115. Ibid.

116. Id., at p. 129.

117. Id., at p. 153.

118. Id., at p. 160.

119. See, Robert Veatch, op. cit., supra, n.48, p.41.

120. See on this point, Roy Branson, "The Scope of Bioethics: Individual and Social" in, Robert M. Veatch and Roy Branson (editors), Ethics and Health Policy, Ballinger Pub. Co., Cambridge, Mass., 1976, 5.

Branson observes, not without some justification, that:

> Paul Ramsey ... assumes that the scope of topics bioethics analyzes will remain limited to the sphere of the physician and research scientist. The ethicist should reflect on basic principles, but on principles relevant to the question, "What ought the doctor to do?" While Ramsey wants bioethics to retain its autonomy, he is willing for physicians and scientists to select the topics for theoretical reflection. (p.7).

He adds that for Ramsey the basic concern is fidelity between individuals, a conclusion supported by the topics addressed in The Patient As Person. He observes about Ramsey's topics and focus:

> ... the researcher and an infant subject of an experiment, the surgeon and a potential donor of an organ for a transplant... His focus in medicine is individual ethics. (p.8).

121. Richard McCormick for example acknowledges that:

> We have been accustomed to think of "medico-moral problems" in terms of decisions about procedures touching the health and life of individual patients. In this sense medical ethics has suffered from the individualism which has infected ethics in general. It has equivalently excluded a whole crucial domain from the area of ethical concern, or at least it has not given proportionate attention to this area. ("Issue Areas For A Medical Ethics Program", in, R. Veatch, et al., (editors), The Teaching of Medical Ethics, Institute of Society, Ethics and the Life Sciences, New York, 1973, 10, at p.112.)

122. Ramsey refers to natural law as a "sub-Christian source of insight", in his, Basic Christian Ethics, Scribner's, New York, 1950, at p.76.

123. That view was recently and compellingly argued in a doctoral thesis by Gary Redcliffe entitled, "The Antinomy of Human Freedom and Moral Restraint in Paul Ramsey's Medical Ethics", Faculty of Religious Studies, McGill University, 1983.

124. Ibid.

125. Regarding Ramsey's "medical indications policy", see especially his, Ethics at the Edges of Life, op. cit., supra, n.101, 145-188. We will be analyzing that policy below in dealing with Zachary (pp.284-298) and Ramsey (362-387).

126. Fletcher, Joseph, "Ethics and Nursing", op. cit., supra, n.104, at p.674. Given Fletcher's focus on the calculation of consequences, Veatch writes that, "In this way, he is closer to the concern of Aquinas for doing good and avoiding evil than most followers of either Aquinas or Fletcher would like to admit". Veatch, op. cit., supra, n.119, at p.42.

127. See Fletcher, Situation Ethics: The New Morality, Westminster Press, Philadelphia, 1966, p.21.

128. Fletcher, "Ethics and Nursing", op. cit., supra, n.104, at p.674.

129. Veatch, op. cit., supra, n.119, at p.42. In discussing Fletcher's views, Kenneth Vaux makes a similar observation in his Biomedical Ethics, op. cit., supra, n.73, at p.21:

> A "Shooting from the gut" ethic now characterizes medicine. It undergirds the impatience of doctors with endless philosophizing which never makes up its mind. It is evidenced in the chafing experienced under drug laws and human experimentation guidelines by physicians. Yet this enduring wisdom has been established at great cost and deserves to be perpetuated.

130. That crucially important difference and its implications for policy-making will be discussed in the next section of this chapter.

131. Ramsey, Paul, op. cit., supra, n.101, at p.xiv.

132. See Paul Ramsey, "The Nature of Medical Ethics", in, op. cit., supra, n.14, p.128.

133. A distinction used by James Rachels in, "Can Ethics Provide Answers?", (1980) 10:3 Hastings Center Report 32.

134. Hare, R.M., "Can the Moral Philosopher Help?", in, Stuart F. Spicker and H.T. Engelhardt, op. cit., supra, n.34, 49, at p.52.

135. See for instance the 1960 U.S. decision of Natanson v. Kline, 186 Kan 393.350 P. 2d. 1093 (1969); 187 Kan. 186, 354 P. 2d 670 (1960). It was held in that decision that:

> A doctor might well believe that an operation or form of treatment is desirable or necessary, but the law does not permit him to substitute his own judgment for that of the patient by any form of artifice or deception.

136. Beauchamp, Thomas L. and McCullough, Laurence B., Medical Ethics: The Moral Responsibilities of Physicians, Prentice Hall, Englewood Cliffs, New Jersey, 1984, at p.44.

137. Hippocrates, "The Art", op. cit., supra, n.29, at p.193.

138. Hippocrates, "Epidemics", op. cit., supra, n.29, at p.165.

139. See, Margaret Somerville, Informed Consent, Law Reform Commission of Canada, Ottawa, Ontario, 1979; Jay Katz, "Informed Consent - A Fairy Tale? Law's Vision", (1977) 39 University of Pittsburgh Law Review; Jay Katz, "Disclosure and Consent in Psychiatric Practice: Mission Impossible?", in, Charles Hofling, (ed.), Law and Ethics in the Practice of Psychiatry, Brunner Mazel Inc., New York, 1981; Hugh R. Faden and Thomas L. Beauchamp, "Decision-making and Informed Consent", (1980) 7 Social Indicators Research, 313-36.

140. See, Beauchamp and McCullough, op. cit., supra, n.136, at p.75.

141. See for instance the use made of the principles of respect for persons, beneficence and justice in the Belmont Report, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, U.S. Government Printing Office, DHEW Pub. No. [OS] 78-0012, 1978, pp.4-10.

142. See for example, Veatch, op. cit., supra, n.48, pp.250-287.

143. Rawls, John, A Theory of Justice, Harvard U. Press, Cambridge, 1971.

144. Among recent bioethical writings, for example, Beauchamp and McCullough (op. cit., supra, n.136) argue that beneficence and autonomy alone can serve as the operative principles for physician decision-making in the clinical setting. Robert Vaux on the other hand (op. cit., supra, n.48) proposes: beneficence, contract keeping, autonomy, honesty, avoiding killing, justice. The same variety is to be found in philosophical ethics generally. For example, G.J. Warnock (The Object of Morality, Methuen, London, 1971) proposes: beneficence, non-maleficence, non-deception and fairness. W.K. Frankena (Ethics, Prentice-Hall, Englewood Cliffs, N.J., 1973) builds his positions on only beneficence and justice.

145. See for example, K. Baier, The Moral Point of View, Random House, New York, 1965. These other characteristics which Baier adds (as does Rawls, op. cit., supra, n.143, pp.130-136) are: generality (to be a principle one should be able to formulate it without having recourse to proper names), ordering (the principles chosen must make it possible to order conflicting claims), and finality (reasoning according to the principles selected must be conclusive). Bok (op. cit., supra, n.42, p.141, n.19) does not include generality or finality, claiming that they are more ideal than possible.

146. Deontological ethics involves holding that there are some rules and principles of action which are valid quite independently of the consequences of actions taken in accord with those rules or principles. As well, it means holding that one must always act

according to those rules. An extreme and rarely appealed-to branch of this theory is <u>act</u>-deontology, which means holding that each act is to be judged entirely on its own merits, apart from either consequences or rules.

A second theory is that of <u>consequentialist</u> ethics. This approach holds that the criterion for judging an action right or wrong is by determining and evaluating the consequences of that action.

The third major ethical theory, in effect a form of consequentialist ethics, is <u>utilitarian ethics</u>. The fundamental principle according to which consequences are to be judged is that of the general happiness of everyone concerned, or the highest net balance of good as opposed to evil. Utilitarians are not necessarily against rules. <u>Rule</u>-utilitarians select and base themselves upon rules of conduct to promote general happiness, whereas <u>act</u>-utilitarians evaluate each individual action as to whether it will or will not promote general happiness.

147. See, <u>supra</u>, p.70-71 for McCormick's distinctions between essential ethics, existential ethics, essential Christian ethics and existential Christian ethics.

148. Gustafson, James, <u>op. cit.</u>, <u>supra</u>, n.105, at p.270.

149. Ramsey, Paul, <u>op. cit.</u>, <u>supra</u>, n.101, at p.xiii. He goes on to add:

> The physicians, lawyers, ethicists, and - most of all - the ordinary concerned citizens to whom I address my analysis and argument need in no way be offended by the religious warrants that are decisive for me. Such a person can read with a view to showing that there is a non-religious replacement for "my neighbour as holy ground" that still sustains an inviolable human dignity.

150. Gustafson, James M., <u>Can Ethics Be Christian?</u>, University of Chicago Press, Chicago and London, 1975, at p.175.

151. See: David Burrell and Stanley Hauerwas, "From System to Story: An Alternative Pattern for Rationality in Ethics", in, Tristram Engelhardt and Daniel Callahan (editors), Knowledge, Value and Belief, Vol. II, The Foundations of Ethics and Its Relationship to Science, Institute of Society, Ethics and the Life Sciences, New York, 1977, 111-152; Stanley Hauerwas, "The Self As Story: A Reconsideration of the Relation of Religion and Morality from the Agent's Perspective", in his, Vision and Virtue - Essays in Christian Ethical Reflection, Fides, Notre Dame, 1975, 68-89.

152. Burrell, David and Hauerwas, Stanley, "From System to Story...", op. cit., supra, n.151, at p.142, n.1. Because Gustafson does not seem to assign importance to the matter of "how" Christian moral principles are accounted for in concluding that the contribution of theology is of minimal importance (supra, p. and n.148), Burrell and Hauerwas take issue with Gustafson. But elsewhere Gustafson does indeed assign importance to the "story factor" in the Christian context. See his, Can Ethics Be Christian?, op. cit., supra, n.150.

153. See for example, Paul Lehmann, Ethics In A Christian Context, Harper & Row, New York, 1963, pp.74-80. Lehmann argues that divine behaviour in the world excludes not only a "preceptual apprehension" of the will of God, but also an abstract apprehension. Christian behaviour cannot be generalized simply because God's will cannot be generalized. While he rejects a "preceptual apprehension" of the will of God, Lehmann does insist upon "concrete human occasions" of obedience, as in the Decalogue; but the Decalogue presupposes the covenant.

154. See for example, Gerhard von Rad, Deuteronomium-Studien, Vandenhoeck und Ruprecht, Goettingen, 1948, 49-50, Myers, J.M., "The Requisites for Response. On the Theology of Deuteronomy", (1961) 15 Interpretation, 14-31; Moran, W.L., "The Ancient Near Eastern Background of the Love of God in Deuteronomy", 1963 25 Catholic Biblical Quarterly, 77-87.

155. See for instance, Mark 7: 6-8.

156. Burrell and Hauerwas ("From System to Story...", op. cit., supra, n.151, pp.137-141) conclude that in effect religious faith amounts to accepting a certain set of stories as canonical. They suggest

> we tend to decide which stories will be canonical for us on the basis of certain criteria, or more exactly, that stories taken by us as canonical will have certain effects on our lives. The criteria or effects they propose are: power to release us from destructive alternatives, ways of seeing through current distortions, room to keep us from having resort to violence, a sense of the tragic and how meaning transcends power.

157. Id., at pp. 113, 114.

158. Burrell and Hauerwas depend for this point on an article by Edmund Pincoffs, "Quandry Ethics", (1971) 80 Mind, 552-71.

159. Burrell and Hauerwas, "From System to Story...", op.cit., supra, n.151, at p.117. Applying this observation specifically to medical ethics, they add:

> What makes "medical ethics" so difficult is the penchant of medical care to force decisions that seem to call into question aspects of our life that we assumed not to be matters of decision, e.g. should we provide medical care for children who are born with major disabilities such as meningomyelocele. In this respect the current interest in medical ethics does not simply represent a response to issues in modern medicine, but also reflects the penchant of the standard account to respond to dilemmas.

Another but similar way of expressing this point that one can assume certain matters are not matters of decision, but "the air we breathe", is what H.R. Niebuhr calls "fittingness". See, H.R. Niebuhr, The Responsible Self, Harper & Row, New York, 1963.

160. Id., at p.118.

161. Id., at p.121.

162. Rachels, James, "Can Ethics Provide Answers?", (1980) 10:3 Hastings Center Report, 32, at p.38.

163. See Burrell and Hauerwas, op. cit., supra, n.151, p.116.

164. Hauerwas, Stanley, "The Christian Society and the Weak: A Meditation on the Care of the Retarded", in his, Vision and Virtue - Essays in Christian Ethical Reflection, Fides, Notre Dame, 1974, 187, at p.191, 193.

165. Barth, Karl, Church Dogmatics, op. cit., supra n. 81 at p. 342.

166. Gustafson, op. cit., supra n. 105 at p. 262.

167. Ibid.

168. Id., at p. 257.

169. Id., at p. 258.

170. Macquarrie, John, Principles of Christian Theology, Scribner's, New York, 1966 at p. 477. J.V. Langmead Casserley (quoted by Macquarrrie) makes the same point:

> The natural law for them must necessarily grow and expand as men's potentialities and responsibilities are deepened and widened through his gradual fulfillment of God's purpose in creating him. Natural law doctrine is not conservative... We might even describe 'natural law' as an existential concept. Natural law is the "insurgent authenticity".

171. Gustafson would telescope these awarenesses and their implications into an attitude we call simply "self-criticism". See Gustafson, op. cit., supra n. 105 at pp. 263-265.

172. Gustafson, James, "The Theologian as Prophet, Preserver or Participant", in his, Theology and Christian Ethics, Pilgrim Press, Philadelphia 1974, 73-96.

173. Id., at pp. 84, 85.

174. Shils, Edward, "The Sanctity of Life", in Daniel H. Labby (ed.), Life or Death: Ethics and Options, U. of Washington Press, Seattle, 1968, at pp. 12-13.

Shils also adds:

> The trancendant sacred is a construction which the human mind itself has created to account for and to place in a necessary order the primordial experience and vicissitudes of the

> actual embodiment of vitality to which it attributes sacredness ... If man did not prize his own vitality, the sacred and the vast symbolic elaboration into cosmogonies and theologies would not exist. (At pp.13, 14).

175. Mitchell, Basil, "Is A Moral Consensus in Medical Ethics Possible?", (1976) 2 Journal of Medical Ethics, 18, at p.23. See also R.M. Hare, "Medical Ethics: Can the Moral Philosopher Help", in, Stuart F. Spicker and H.T. Engelhardt, (eds.), op. cit., supra, n.34, 49-61.

176. See, H. Tristram Engelhardt, "Bioethics in Pluralist Societies", (1982) 26 Perspectives in Biology and Medicine, 64-77.

177. Shils, op. cit., supra, n.174.

178. See for example, Marvin Kohl (ed.), Beneficent Euthanasia, Prometheus Books, Buffalo, N.Y., 1975, 130-141; "Understanding the Case for Beneficent Euthanasia", (1973) 1 Science, Medicine and Man, 111-121. See also H.T. Engelhardt, "Ethical Issues in Aiding the Death of Young Children", in Kohl (ed.), 180.

179. Hippocrates, "The Art", Jones, (Trans.), p.

180. Canadian Medical Association, Code of Ethics, approved by General Council, 1982.

181. It should however be noted that medical associations have in some cases attempted to further refine that general policy, for instance in the form of what are usually referred to as "no resuscitation guidelines". But such guidelines are restricted to cases when the patient is terminally ill or dying and do not acknowledge any other circumstances for which treatment might be stopped.

182. For more on this role of abstract principles vis-à-vis moral rules, see Henry David Aiken, Reason and Conduct, Alfred A. Knopf, N.Y., 1962, especially Chapter 4, "Levels of Moral Discourse". See also, Daniel Callahan, "The Sanctity of Life", in, Donald R. Cutler, (ed.), Updating Life and Death, Beacon Press, Boston, 1968. For a summary and application

of this approach see Edward Keyserlingk, Sanctity of Life or Quality of Life, Law Reform Commission of Canada, Minister of Supply and Services, Ottawa 1979, 37-47.

183. Supra, pp. 143-156.

184. The term "congenital abnormality" has been defined as follows: morphologic abnormalities of internal or external organs arising before birth that have actual or potential clinical significance. See, James B. Wyngaarden and Lloyd H. Smith, Cecil Textbook of Medicine, W.B. Saunders Co., Philadelphia, 1982, at p.22.

185. Rock, J. and Hertig, A.T., "Some aspects of early human development", (1942) 44 American Journal of Obstetrics & Gynecology, 973.

186. Emery, A.E.H., Elements of Medical Genetics, 3rd ed., Churchill Livingstone, Edinburgh, 1974.

187. Drillien, C.M., "Studies in prematurity, stillbirth and neonatal death. Part 2. Factors affecting birth weight and outcome", (1947) 54 J. Obstet. Gynecol. Br. Commonwealth, 300.

188. Nishimura, H., et al., "High incidence of several malformations in early human embryos as compared with infants", (1966) 10 Biol. Neonate 93; Carr, D.H., "Chromosome studies in spontaneous abortions", (1965) 26 Obstetrics and Gynecology, 308.

189. Milunsky, Aubrey, and Alpert, Elliot, "Maternal Serum AFP Screening", (1978) 298 New England Journal of Medicine, 738.

190. Swinyard, Chester A., et al., "Spina Bifida as a prototype defect for decision-making: nature of the defect", in, Chester A. Swinyard (ed.), Decision Making and the Defective Newborn, Charles C. Thomas, Springfield, Ill., 1978, 17, at p.26.

191. See, William L. Nyhan and Edward Edelson, The Hereditary Factor, Grosset & Dunlap, N.Y., 1976, 128-129; William L. Nyhan and Nadia O. Sakati, Genetic and Malformation Syndromes in Clinical Medicine, Year Book Med. Pub. Inc., Chicago, 1976, at p.21.

192. Office of Technology Assessment, U.S. Congress, The Costs and Effectiveness of Neonatal Intensive Care (Case Study #10), U.S. Government Printing Office, Washington, 1981, at p.11. For some additional figures and comparisons, see, A.R. Jonsen, "Ethics the Law and the Treatment of Seriously Ill Newborns", in, E. Doudera (ed.), Legal and Ethical Aspects of Treating Critically Ill and Terminally Ill Patients, AUPHA Press, Ann Arbour, Mich., 1982, 236.

193. Shapiro, S., et al., "Relevance of Correlates of Infant Deaths for Significant Morbidity at 1 Year of Age", (1980) 136 American Journal of Obstetrics & Gynecology, 363. It is also reported that newborns weighing less than 1500 grams account for almost half of all infant deaths although they constitute only one percent of all newborns, and under 750 grams the mortality rate is nearly 100%. See, op. cit., supra, n.9, at p.11.

194. In Canada there were reported to be 29 such units in place in 1980 with others under construction or being planned, the average unit having twenty beds and having some 400 admissions annually. See Joseph E. Magnet, "Withholding Treatment from Defective Newborns: A Description of Canadian Practices", (1980) 4 Legal Medical Quarterly 271. In the United States, a 1981 study reported that there are at least 7,500 neonatal intensive care unit beds in approximately 600 hospitals across the country See, Office of Technology Assessment, supra, n.192, at pp. 7, 15.

195. It is reported that in the United States six percent of children born alive go to one of these units and stay for an average of 8-18 days, that the average cost of this care is $8,000, and that $1.5 billion was spent on neonatal intensive care in 1978. See, Office of Technology Assessment, op. cit., supra, n.192, at pp. 15, 19. For Canada a 1975 study reported that at one such unit the average stay was seven days, followed by convalescent care of twenty-five days, at an average cost of $5,350. See, P. Sawyer, The Intensive Care of the Newly Born, New York, 1975, at p.181.

196. See for example, Peter P. Budetti and Peggy McManus, "Assessing the Effectiveness of Neonatal Intensive Care", (1982) 20 Med. Care 1027.

197. Shaw, Anthony, et al., "Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons", (1977) 60 (No. 4, Part 2) Pediatrics, 588, at p.589.

198. Id., pp.589, 590. It is of course difficult to determine the significance of religious affiliation without knowing in the case of each respondent his or her degree of "religiosity", that is, the degree to which they are committed to the particular (medical) ethical stances of their particular religious tradition or denomination, and which particular stance within that tradition or denomination when more than one is accepted as legitimate. It is nevertheless interesting to note that the Jewish pediatricians responding to this question from both groups do not reflect bioethics as outlined above in Part One.

199. Id., at p.594.

200. Duff, Raymond S., "Counselling Families and Deciding Care of Severely Defective Children: A Way of Coping With 'Medical Vietnam'", (1981) 67 Pediatrics 315, at p.317. What allows us to consider the views expressed by Duff in this article as at least somewhat representative of the views of many other pediatricians, is that the paper was apparently presented to and generally approved by pediatricians in five major medical centers. See "Addendum" to the article, p.320.

201. Id., at p.318.

202. Id., at p.317.

203. Duff, Raymond S., and Campbell, A.G.M., "On Deciding the Care of Severely Handicapped or Dying Persons; With Particular Reference to Infants", (1976) 57 Pediatrics 487.

204. Id., at p.487, Abstract.

205. Duff, Raymond S., op. cit., supra, n.200, at p.319.

206. Id., at p.318.

207. Duff, Raymond S. and Campbell, A.G.M., "Social Perspectives on Medical Decisions Relating to Life and Death", in, John Ladd (editor), Ethical Issues Relating to Life and Death, Oxford U. Press, New York, 1979, 187, at p.188.

208. Id., at p.198, where they appear to agree with that viewpoint in the quote from Dr. W. Zuelzer, in his, "Medicine and Ethics: Part III", (1974) 25 News and Comment, American Academy of Pediatrics, 10-12. See

also, Duff and Campbell, "Moral and Ethical Dilemmas in the Special Care Nursery", (1973) 289 <u>New England Journal of Medicine</u>, 890-94.

209. Fost, N., "Counseling Families Who Have A Child With A Severe Congenital Anomaly", (1981) 67 <u>Pediatrics</u> 321 at p.324.

210. Crane, Diana, <u>The Sanctity of Social Life: Physicians' Treatment of Critically Ill Patients</u>, Russell Sage Foundation, New York, 1975 at pp.45-46.

211. <u>Id</u>., p.70.

212. <u>Id</u>., pp.96-101.

213. <u>Id</u>., at p.101.

214. Shaw, <u>et al.</u>, <u>op. cit.</u>, <u>supra</u>, n.197, p.590.

215. Todres, I. David, <u>et al</u>., "Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns", (1977) 60 <u>Pediatrics</u> 197, at p.198.

216. "Treating the Defective Newborn: A Survey of Physicians' Attitudes", (1976) 6:2 <u>Hastings Center Report</u>, 2.

217. Since a Down's syndrome newborn without complications does not have a life-threatening condition, it is not at all clear how the responding physicians could prefer and effect "passive" euthanasia in such cases, i.e. "allowing" to die.

218. Duff, Raymond S., <u>op. cit.</u>, <u>supra</u>, n.200 at p.317.

219. Shaw, <u>et al.</u>, <u>op. cit.</u>, <u>supra</u>, n.197 at pp.589-590.

220. Todres, <u>et al</u>., <u>op. cit.</u>, <u>supra</u>, no.215.

221. Todres, <u>et al</u>., base this explanation on the findings of G.H. Zuk in "Religious Factors and the Role of Guilt in Parental Acceptance of the Retarded Child", (1960) 64 <u>Am. J. Ment. Defic</u>. 139.

222. Crane D., <u>op. cit.</u>, <u>supra</u>, n. 210 at p.158.

223. <u>Id</u>., at p.178.

224. <u>Id</u>., p.176.

225. <u>Id</u>., p.158.

226. Id., p.55.

227. Id., p.56.

228. Todres, et al., op. cit., supra, n.215.

229. Magnet, Joseph E., op. cit., supra, n.194, p.279.

230. Ibid.

231. For example the family status criterion was referred to by Shurtleff, et al., who write: "For an initial decision to offer maximum therapy the following points were considered ... a family (i.e. natural parents) with economic and intellectual resources living within reach of appropriate medical facilities...", D.B. Shurtleff, et al., "Myelodysplasia: Decision for Death or Disability", (1974) 291 New England Journal of Medicine, 1005 See also J. Lorber, "Results of the Treatment of Myelomeningocele", (1971) 13 Dev. Med. Child Neurol., 279, 290.

232. See on this point, Warren T. Reich, "Quality of Life and Defective Newborn Children: An Ethical Analysis", in, Chester A. Swinyard, editor, Decision Making and the Defective Newborn, Charles C. Thomas, Springfield, Ill., 1978, 489, 495.

233. Gustafson, James M., "Mongolism, Parental Desires, and the Right to Life", (1973) 16 Perspectives in Biology and Medicine, 529, at p.530.

234. Todres, et al., op. cit., supra, n.215, pp.198-199.

235. Ibid.

236. Shaw, et al., op. cit., supra, n.197, p.590.

237. Judicial Council of the American Medical Association, Current Opinions, American Medical Association, Chicago, 1982.

238. See the various articles by Duff, or Duff and Campbell referred to above in notes 200, 203, 207 and 208.

239. For some examples of cases in which parents are often not fully informed or involved, see Magnet, op. cit., supra, n.194, pp.273-276, 280-282.

240. See for example, A. Shaw, "Dilemmas of 'Informed Consent' in Children", (1973) 289 New England Journal of Medicine, 886; G.B. Avery, Neonatology: Pathophysiology and Management of the Newborn, Lippincott, Philadelphia, 1975. Avery writes (at p.12): "... it is unfair to place the whole burden of decision on the parents. Regardless of the outcome, the parents will feel guilty and will need compassionate support".

241. See for example, D.G. Benfield, et al., "Grief Responses of Parents to Neonatal Death and Parent Participation in Deciding Care", (1978) 62 Pediatrics 171. His findings in fact indicated that parents who were informed and involved showed less anger and depression than those not involved.

242. One pediatrician for example writes, "The parents are usually too emotionally involved to make an objective decision alone". See, M.T. Stahlman, "Ethical Dilemmas in Perinatal Medicine", (1979) 94 Journal of Pediatrics, at p.519.

243. See for instance, R. Darling, "Parents, Physicians and Spina Bifida", (1977) 7:4 Hastings Center Report, 10; R. Duff and A.G.M. Campbell, op. cit., supra, n.208.

244. See on this point, Carson Strong, "The Neonatologist's Duty to Patient and Parents", (1984) 14:4 Hastings Center Report, 10.

245. Those ethicists and others who argue that unilateral decisions by physicians are always paternalistic do not generally acknowledge and consider that the physician has duties to both the infant and the parents, and that the former may sometimes take precedence over the latter. See for example A. Buchanan, "Medical Paternalism", (1978) 7 Philosophy and Public Affairs, 370.

246. Strong, op. cit., supra, n.244, at p.16.

247. Id., at p.15.

248. Ibid.

249. It would appear that predictions of the disruptive effects on families who keep their seriously disabled infants are sometimes unduly pessimistic. One British

study of the impact on their families of severely disabled infants concluded that the disruption thereby imposed on the families in these cases was not great. See G Hunt, "Implications of the Treatment of Myelomengocele for the Child and His Family", (1973) 2 Lancet 1308. Another British study concluded that in a great majority of cases parents felt that having their disabled child with them had brought them closer together. See, E.H. Hare, et al., "Spina Bifida Cystica and Family Stress", (1966) 3 British Medical Journal 757. See also, M. Voysey, A Constant Burden: The Reconstitution of Family Life, Routledge and Keagan Paul, London, 1975. Darling (op. cit , supra, n.243 at p.10), a sociologist, concludes on the basis of her research that: "Almost without exception, all the parents I interviewed defined their situation in a positive manner. They did not generally express unqualified enthusiasm, but neither did they see themselves as unfortunate victims of tragedy ... By far the most important influence on parental attitudes seems to have been interaction with the child himself."

250. Duff, for example, writes: "Deprived of a loving home, the severely handicapped child's life in a series of foster homes or an institution would be too miserable. Choosing death sometimes is viewed as an act of love because some life can only be wrongful". See, R. Duff, op. cit., supra, n 200, at p.316.

251. Fost, Norman, "How Decisions are Made: A Physician's View", in, Chester A. Swinyard, M.D., (ed.), Decision Making and the Defective Newborn, Charles C. Thomas, Springfield, Ill., 1978, 220, at p.228. Duff, who as already noted emphasizes in effect the physician's role as parent advocate, predictably disagrees with separating the care and custody decisions. He writes that, "... this suggestion is simplistic and misleading because in real life, professional, legal, economic, personal, family, religious and social interrelationships are enormously complex. Altering custody arrangements may frustrate parent-child "bonding" which is extremely important for all children. Besides, any pretense that anyone can make conflict-free decisions is a dangerous illusion." See, R. Duff, op. cit., supra, n.200, at p.317. Conflict-free decisions are of course unlikely. But separating considerations of care and treatment from those of custody to the extent possible is at least an important step towards reducing conflicts of interest to the minimum.

252. Duff and Campbell observe for example about their own special-care nursery:

> When maximum care treatment was viewed as unacceptable by families and physicians in our unit, there was a growing tendency to seek early death as a management option, to avoid that cruel choice of gradual, often slow, but progressive deterioration of the child who was required under these circumstances in effect to kill himself. Parents and the staff then asked if his dying needed to be prolonged. If not, what were the most appropriate medical responses?

Duff and Campbell do not themselves answer that very good question.

253. A. Shaw, _et al_., _op. cit_., _supra_, n.197, at p.592.

254. _Ibid_.

255. J.E. Magnet, _op. cit_., _supra_, n.194, pp.283-284.

256. _Id_., at p.283. A similar view has been expressed by Dr. Lorber, who stated:

> It is essential at this point to state clearly that one hopes that those who are not treated should not live long. It is imperative that non-treatment should really be non-treatment, not just no operation. Nothing should be done to prolong life, no incubators, no tube feeding, no antibiotic drugs, and most certainly no resuscitation.

See J. Lorber, "The Doctor's Duty to Patients and Parents in Profoundly Handicapping Conditions", in D. Roy (ed.), _Medical Wisdom and Ethics in the Treatment of Severely Defective Newborn and Young Children_, Eden Press, Montreal, 1978, at p.21.

257. _Ibid_. Magnet (_op. cit_., _supra_, n.194) also reports that his interviews indicate there is a controversy with regard to pain-killing drugs. Because there is uncertainty about the extent of the infant's ability to experience pain, there are different practices in various units with respect to the use of drugs such as morphine and demerol.

258. D. Crane, _op. cit_., _supra_, n.210, pp.71-72.

259. _Id_., at p.200.

260. A. Shaw, _et al_., _supra_, n.197, pp.592-593.

261. I.D. Todres, _et al_., _supra_, n.215, p.199.

262. Duff, Raymond S. and Campbell, A.G.M., "Moral and Ethical Dilemmas: Seven Years into the Debate About Human Ambiguity", in, M. Bayles and D.M. High (editors), Medical Treatment of the Dying: Moral Issues, Schenkman, Cambridge, Mass, 1983, 153 at p.162.

263. J.E. Magnet, op. cit., supra, n.194, p.284.

264. Ibid.

265. "Grief Prompted MD's Mercy-Killing of Infant", Ottawa Citizen, May 26, 1983.

266. "Giving Morphine not Uncommon: Nurse", Globe and Mail, January 16, 1984, p.4. See also, Transcript of the Candace Lynn Taschuk Inquiry, Mr. Justice Rolf of the Provincial Court of Alberta presiding, 1983.

267. See supra, n.252, for the relevant quote from Duff and Campbell.

268. R.S. Duff and A.G.M. Campbell, op. cit., supra, n.203, at p.489.

269. Id., at p.492.

270. R.S. Duff and A.G.M. Campbell, op. cit., supra, n.207, at p.203.

271. R.S. Duff and A.G.M. Campbell, op. cit., supra, n.262, at p.162.

272. Tooley, M., "Decisions to Terminate Life and the Concept of Person", in J. Ladd (ed.), Ethical Issues Relating to Life and Death, Oxford U. Press, New York, 1979, at p.80.

273. Warner, R., Morality in Medicine, Alfred Pub.Co., Sherman Oaks, Calif., 1980, at p.79.

274. As Gustafson observed, "... once an infant is born its independent existence provides independent value in itself, and those who brought it into being and those professionally responsible for its care have an obligation to sustain its life regardless of their negative or ambiguous feelings toward it". James Gustafson, op. cit., supra, n.233, at p.550.

275. In so defining without further justification our meaning of treatment policies in the strict sense, it is assumed that their various components are more or less self-evident and/or already established by much of what has been argued in this thesis to this point. Without the existence and regular application of normative criteria, arbitrariness is the inevitable result, and the protection of the interests of affected parties, especially the weakest and most vulnerable, even with the best will in the world is less likely. Fost has expressed this point well: "Dr. Duff has been asked, 'What is to prevent families from deciding <u>arbitrarily</u> that a child shouldn't be kept alive?' He says, 'The doctors won't allow it.' I see institutions where children with Down's syndrome, or myelomeningocele with an excellent prognosis, are allowed to starve, without specific criteria as to who is in this class and without a defined process for decision-making. What is the definition of arbitrary if not the absence of criteria or a defined process?" N. Fost, <u>op. cit.</u>, <u>supra</u>, n.251, at p.228.

276. See especially: John Lorber, "Results of Treatment of Myelomeningocele: An Analysis of 524 Unselected Cases, With Special Reference to Possible Selection for Treatment", (1971) 13 <u>Developmental Medicine and Child Neurology</u> 279; "Spina Bifida Cystica: Results of Treatment of 270 Consecutive Cases with Criteria for Selection for the Future", (1972) 47 <u>Archives of Disease in Childhood</u> 854; "Early Results of Selective Treatment of Spina Bifida Cystica", (1973) 4 <u>British Medical Journal</u> 201; "Criteria for Selection of Patients for Treatment", Abstract, Fourth International Conference on Birth Defects, Vienna, Austria, 1973; "Selective Treatment of Myelomeningocele: To Treat or Not to Treat", (1974) 53 <u>Pediatrics</u> 307; "Critical Problems in the Management of Myelomeningocele and Hydrocephalus", (1975) 10 <u>Journal of the Royal College of Physicians</u> 47; "The Doctor's Duty to Patients and Parents in Profoundly Handicapping Conditions", in David J. Roy (ed.), <u>Medical Wisdom and Ethics in the Treatment of Severely Defective Newborn and Young Children</u>, Eden Press, Montreal, 1978, 9.

277. Regarding that earlier extreme of an excessive number of deaths, whereas Lorber attributes that state of affairs simply to lack of expert care, Freeman goes further and concludes that before aggressive treatment of spina bifida became possible (about 1950) a

significant proportion of the deaths were the result of infant euthanasia, by omission or commission. See, John M. Freeman, "To Treat or Not to Treat: Ethical Dilemmas of Treating the Infant With A Myelomeningocele", (1973) 20 Clinical Neurosurgery, 134, 136.

278. Lorber, J., "Results of Treatment of Myelomeningocele", (1971) 13 Developmental Medicine and Child Neurology 279, at p.279.

279. Id., at p.288.

280. Lorber claims a large part of the responsibility for a "second revolution in the management of myelomeningocele", and claims that his principles and policy have been almost universally accepted in Britain by physicians, nurses, and even the Department of Health and Social Security. See his, "Early Results of Selective Treatment of Spina Bifida Cystica", (1973) 4 British Medical Journal 201, at p.202.

281. Lorber, op. cit., supra, n.278, at p.288.

282. Id., at p.299.

283. Id., at p.296.

284. See, Lorber, op. cit., supra, n.280. Specifically, the physical signs at birth which Lorber uses as his adverse criteria are these:

(1) Gross paralysis of the legs, paralysis below third lumbar segmental level with at most hip flexors, adductors, and quadriceps being active.

(2) Thoracolumbar or thoracolumbosacral lesions related to vertebral levels.

(3) Kyphosis or scoliosis.

(4) Grossly enlarged head, with maximal circumference of 2 cm or more about the 90th percentile related to birth weight.

(5) Intracerebral birth injury.

(6) Other gross congenital defects - e.g. heart disease, ectopia of bladder, and mongolism.

285. Lorber, J., "Selective Treatment of Myelomeningocele: To Treat or Not to Treat", (1974) 53 Pediatrics 307.

286. See for example, John M. Freeman, "The Shortsighted Treatment of Myelomeningocele: A Long Term Case Report", (1974) 53 Pediatrics, 311-313.

287. One of these stages is after the lesion has been clos~~ed~~, during the newborn period. An adverse indication for (continued) treatment would be that of an infant who already has a serious neurological handicap and is now found to have meningitis or ventriculitis. Another stage is that of any life-threatening problem in a severely handicapped child who has gross mental and physical defects. See, Lorber, op. cit., supra, n.280, p.204.

288. Lorber, op. cit., supra, n.280, p.201.

289. Veatch, Robert, "The Technical Criteria Fallacy", (1977) 7:4 Hastings Center Report 15, at p.15.

290. Spicker, Stuart F., and Raye, John R., "The Bearing of Prognosis on the Ethics of Medicine: Congenital Anomalies, the Social Context and the Law", in, Stuart F. Spicker, et al., (editors), The Law - Medicine Relation: A Philosophical Exploration, D. Reidel Pub. Co., Dordrecht, Holland, 1981, 189, at p.201.

291. Lorber, op. cit., supra, n.280.

292. Darling, op. cit., supra, n.243, at p.13.

293. Darling reports this comment from the father of a child with an extreme form of psychomotor retardation: "I can't imagine life without her ... The thing I dread most is her death. We know we will lose her someday, and that is the worst thing". Id., at p.11.

294. Lorber himself expresses clearly that gloomy medical assessment of conditions (and hence people) which cannot be fixed:

> There is, however, no advance in sight which could make more than a marginal difference to the quality of the survivors with adverse criteria. No amount of orthopedic skill could create muscle power where the spinal cord has failed to develop; no medical or surgical

> treatment of extreme hydrocephalus could restore lost brain function; and no method of treatment could lead to an acceptable quality of life in infants with gross multiple malformations.

Lorber, J., "Spina Bifida Cystica: Results of Treatment of 270 Consecutive Cases with Criteria for Selection for the Future", (1972) 47 Archives of Disease in Childhood, 854, at p.872.

Another similar view of a physician is reported by Darling:

> It's hard to find much happiness in this area. The subject of deformed children is depressing. Other problems I can be philosophic about. As far as having a mongoloid child ... I can't come up with anything satisfying about it, I can't think of anything good it does. It's not fun or pleasant, it's somebody's tragedy. I can find good things in practically anything - even dying - but birth defects are roaring tragedies ... Maybe if I was trained differently I'd have a different outlook.

Darling, R., op. cit., supra, n.243, at p.11.

295. Lorber (op. cit., supra, n.278, at p.300) writes:

> It may be feared that selection for treatment may lead to the early death of an infant who has at least a chance of normal intellectual development. The data presented here indicate that with modern advances in treatment this is possible in a minority of even the most seriously disabled infants. Twenty percent of all 110 infants with major adverse criteria at birth were of normal intellectual development at 2-4 years of age....

296. Lorber, J., "Ethical Problems in the Management of Myelomeningocele and Hydrocephalus", (1975) 10 Journal of the Royal College of Physicians, 47, at p.54.

297. Roy, David J., "Defective Babies: Quality of Life, The Measure of Care?", in David J. Roy (editor), Medical Wisdom and Ethics in the Treatment of Severely Defective Newborn and Young Children, Eden Press, Montreal, 1978, 77, at p.92.

298. See, J. Glover, Causing Death and Saving Lives, Penguin Books, 1977, 150-169; R.M. Hare, "Survival of the Weakest", in S. Gorovitz, et al., (editors), Moral Problems in Medicine, Prentice-Hall, Englewood Cliffs, New Jersey, 1976, 364-369.

299. As an example of cases described in detail partly in order to suggest the suffering and pain involved, he refers to a:

> "normally intelligent girl of 9 years of age who has had 18 major operations, including 7 revisions of her shunt and two extensive spinal osteotomies in an attempt to correct her extreme kyphoscoliosis. A long metal rod was passed through the bodies of her vertebrae along the length of the vertebral column: unfortunately she had such a compensatory lordosis that this rod emerges from the thoracic vertebrae and through the skin to bridge the lumbar lordosis and enter the lowest lumbar vertebrae and sacrum."

Lorber J., op. cit., supra, n.278, at p.284.

300. Dr. R.B. Zachary of the Children's Hospital in Sheffield writes that, "I personally have seen little evidence that the babies have pain in the newborn period". See his, "Life With Spina Bifida", (1977) 2 British Medical Journal, 1460, at p.1461.

301. As Spicker points out (op. cit., supra, n.290, at p.202) that is the case even with studies otherwise supportive of Lorber's prognostic data, for example, Gordon D. Stark and Margaret Drummond, "Results of Selective Early Operation in Myelomeningocele", (1973) 48 Archives of Disease in Childhood, 676, at p.680.

302. Lorber, J., "The Doctor's Duty to Patients and Parents in Profoundly Handicapping Conditions", in David J. Roy (editor), Medical Wisdom and Ethics in the Treatment of Severely Defective Newborns and Young Children, Eden Press, Montreal, 1978, 9, at p.21.

303. One such observation was by Zachary, reported by Paul Ramsey in his, Ethics at the Edges of Life, New Haven, 1978, at p.196. Zachary writes:

> It appears that a policy has been adopted by some doctors of giving these babies chloral hydrate or phenobarbitone and in some cases go on to morphia (in the form of Nepenthe) in quite substantial doses and the babies are then fed on demand. Naturally, if the baby is very sleepy it will not demand any food and is likely to die either directly from starvation or from infection in a malnourished infant. Now it is absolutely clear that there is no therapeutic indication for the administration of chloral hydrate or phenobarbitone or morphia and its administration would certainly not be considered in other cases which were to receive treatment... It is not surprising therefore that many of the babies die within a few weeks and hence there is the discrepancy between the results of conservative treatment in some places and others. (See also infra, n.335).

304. Lorber, J., op. cit., supra, n.285, at p.308.

305. Lorber, J., op. cit., supra, n.296, at p.57.

306. See, J. Freeman, "Ethics and the Decision Making Process for Defective Children", in David J. Roy (ed.), Medical Wisdom and Ethics in the Treatment of Severely Defective and Newborn Children, Eden Press, Montreal, 1978, 25, at p.28; J. Freeman, et al., "Decision Making and the Infant with Spina Bifida", in, C.A. Swinyard (ed.), Decision Making and the Defective Newborn, Charles C. Thomas, Springfield, Ill., 1978, 95, at pp.99-100.

307. See especially: "Is There A Right to Die - Quickly?", (1972) 80 Journal of Pediatrics, 904, "To Treat or Not to Treat", in R.H. Wilkins (ed.), Clinical Neurosurgery: Proceedings of the Congress of Neurological Surgeons, (Denver, Colorado, 1972), Williams and Wilkins, Baltimore, Maryland, 1973, 134; "To Treat or Not to Treat: Ethical Dilemmas of Treating the Infant With a Myelomeningocele". (1973) 20 Clinical Neurosurgery, 143; "The Shortsighted Treatment of Myelomeningocele: A Long Term Case Report", (1974) 53 Pediatrics, 311; Practical Management of Meningomyelocele, University Park Press, Baltimore, 1974;

"Ethics and the Decision Making Process for Defective Children", in David J. Roy (ed.), Medical Wisdom and Ethics in the Treatment of Severely Defective Newborn and Young Children, Eden Press, Montreal, 1978, 25; "Decision Making and the Infant with Spina Bifida", in C.A. Swinyard (ed.), Decision Making and the Defective Newborn, Charles C. Thomas, Springfield, Illinois, 1978, 95.

308. See especially J. Freeman, et al., "Decision Making and the Infant with Spina Bifida", in C.A Swinyard (ed.), Decision Making and the Defective Newborn, Charles C. Thomas, Springfield, Illinois, 1978, 95.

309. His concern is "... not to promulgate a specific course of action, but to analyze the decision-making process involved, so that each physician faced with the problem may utilize a similar process to reach his own conclusions about what course of action is in the best interest of his patient". Id., at p.96.

310. Id., at p.102.

(The definitions of impairment and disability used by Freeman are taken from, American Medical Association, "Guides to the Evaluation of Permanent Impairment - The Central Nervous System", (1963) 85 Journal of the American Medical Association, 104.)

311. Freeman, Ibid.

312. Ibid.

313. Id., at p.103.

314. Ibid.

315. Freeman, J., "The Shortsighted Treatment of Myelomeningocele: A Long Term Case Report", (1974) 53 Pediatrics, 311, at p.312.

Lorber acknowledges that applying his adverse criteria policy sometimes leads to this result and is therefore a well-founded fear, "... but experience in several large series indicates that only a very small minority of such untreated infants would survive long". See, J. Lorber, op. cit., supra, n.285, at p.308. However, it should be recalled that a reason why those institutions using Lorber's selective criteria find that their untreated infants die quickly in comparison to those places using more conservative criteria, is that the former keep their infants sedated, resulting in less demand to be fed and early death.

Freeman himself, who does not advocate keeping untreated spina bifida infants sedated, observes the following: "What happens if you don't treat? Do they die quickly? ... How quick is quickly? Note that 10-20 percent are surviving at one or two years, waiting patiently. Only Dr. Lorber's patients are dead by nine months. With the gentle help of sedation and feeding on demand his children starve to death without making too much noise." See, Freeman, J., "Ethics and the Decision Making Process for Defective Children", op. cit., supra, n.306, at p.36.

316. Freeman, J., (ed.), Practical Management of Meningomyelocele, University Park Press, Baltimore; 1974, at p.21.

317. Commentators and critics of Freeman's treatment policy appear to have overlooked this important reason, they focus exclusively on his promotion of vigorous treatment because active euthanasia is illegal. See for example S.F. Spicker, et al., op. cit., supra, n.290, pp.199-200; W.T. Reich, op. cit., supra, n.232, pp.493-495.

318. Freeman, J., et al., op. cit., supra, n.308, at p.109.

319. Freeman, J., "Is There A Right To Die - Quickly?", (1972) 80 Journal of Pediatrics, 904, at p.905.

320. Ibid.

A further argument Freeman makes in favour of legalizing active euthanasia is based on the legality of abortion for a fetus discovered to have a genetic defect. "If it is permissible to kill a fetus at 20 to 24 weeks, should it not also be permissible to kill such an infant at 40 weeks of gestation?" Ibid.

321. Some critics of Freeman's policy appear to read Freeman differently than we do on this point. Reich for example (op. cit., supra, n.232, pp.494-495) implies that Freeman does sometimes put the alleged rights of others to be free of suffering before the infant's right to life. We disagree with Reich, especially if one attends to the full context of Freeman's views and policy.

322. J. Freeman, "Ethics and the Decision Making Process for Defective Children", op. cit., supra, n.306, at p.34.

323. Id., at p.27 and pp.34-35.

324. He observes in that regard (Id., at p.29):

> The child growing up with a disability or handicap has a far different perception of his quality of life than an adult who suddenly becomes disabled or handicapped. Do we even have the ability to project ourselves into such a child's situation? Perhaps, rather than condemning that quality of life, we should seek to improve it, to minimize handicaps where we can do little about impairment. There are differences between handicap and impairment.

325. See especially: R.B. Zachary, "Ethical and Social Aspects of Treatment of Spina Bifida", (August 3, 1968) The Lancet, 274; "The Neonatal Surgeon", (1976) 2 British Medical Journal 866, "Life With Spina Bifida", (1977) 2 British Medical Journal 1460; "Spina Bifida: To Treat or Not to Treat? Give Every Baby A Chance", (September 14, 1978) 147:11 Nursing Mirror 17, "Selective Non-Treatment of Newborn Infants" [letter] (January 21, 1984) 140:2 Medical Journal of Australia 116; R.B. Zachary and W.J.W. Sharrard, "Spinal Dystraphism", (1967) 43 Postgraduate Medical Journal 731; Lister J., Zachary, R.B., Brereton, R., "Open Myelomeningocele - A Ten Year Review of 200 Consecutive Closures", (1977) 10 Progress in Pediatric Surgery 161.

326. That is the label applied to Zachary's policy by Spicker, op. cit., supra, n.290, at pp.206-207.

327. That is the label given to the Zachary policy by Ramsey in his Ethics at the Edges of Life, op. cit., supra, n.13, at pp.181-188.

328. See, R.B. Zachary, "Ethical and Social Aspects of Treatment of Spina Bifidia", (August 3, 1968), The Lancet, 274; R.B. Zachary and W.J.W. Sharrard, "Spinal Dysraphism", (1967) 43 Postgraduate Medical Journal 731, at p.732.

329. Zachary, R.B., "Ethical and Social Aspects of Treatment of Spina Bifida", supra, n.328, at p.274.

330. Ibid.

331. Zachary, R.B., "The Neonatal Surgeon", (1976) 2 British Medical Journal, 866, at p.869.

332. Zachary, R.B., "Ethical and Social Aspects of the Treatment of Spina Bifida", op. cit., supra, n.328, at p.274.

333. Id., at p.276.

334. See, R.B. Zachary, "Selective Non-Treatment of Newborn Infants", [letter], (January 21, 1984) Medical Journal of Australia, 116.

335. Zachary maintains that the main reason why some pediatricians can claim that there is such a high mortality of those children they select for non-treatment is the administration of excessive amounts of sedative:

> ... these babies are receiving 60 mg/kg body weight of chloral hydrate, not once but four times a day. This is eight times the sedative dose of chloral hydrate recommended in the most recent volume of Nelson's Paediatrics and four times the hypnotic dose, and it is being administered four times every day. No wonder these babies are sleepy and demand no feed, and with this regimen most of them will die within a few weeks, many within the first week. It is sometimes said that the chloral hydrate is being administered for pain ... but I personally have seen little evidence that the babies have pain in the newborn period, nor have I found them unable to sleep ... In another centre only one of 24 patients was operated on - all the others died. When asked, "Did they fall or were they pushed into death", the reply was, "They were pushed of course". At another meeting I attended a paediatrician was asked by a medical student what was his method of management, and the reply was, "We don't feed them".

Zachary, R.B., "Life With Spina Bifida", (1977) 2 British Medical Journal, 1460, at p.1461. (See also supra, n.303).

336. While Zachary acknowledges that the results of early operation do favour surgery as far as mortality is concerned, he points out that it should not be concluded that the operation alone accounts for the good survival rates. A contributing factor is the active ~~treatment~~ provided to surgical patients, e.g. infections are treated vigorously and better attention is paid to the renal tract than for those not operated upon. He concludes: "I do not think it has been proved, from a concurrent study of two large series of cases, that the mortality is less in those receiving early operation than in those who do not have early operation but, in every other respect, receive the same care and attention as the surgical series". Zachary, "Ethical and Social Aspects of Treatment of Spina Bifida", supra, n.328, at p.274; when good, ordinary baby care is provided, including treatment of infections, to those not operated upon, the survival rates have been shown to be high. See, M.F. Robards, et al., "Survival of Infants With Unoperated Myelocele", (1975) 4 *British Journal of Medicine*, 12.

337. Zachary, R.B., and Sharrard, W.J.W., op. cit., supra, n. 328, at p.733.

338. See, R.B. Zachary, op. cit., supra, n.335, at pp.1461-1462; op. cit., supra, n.331, at p.869; "Spina Bifida: To Treat or Not to Treat - Give Every Baby A Chance", (September 14, 1978) 147:11 *Nursing Mirror* 17, at pp.18-19.

339. Zachary observes in this regard:

> Most of the survivors who have had a severe meyelomeningocele will still remain severely handicapped - they will have considerable weakness of the lower limbs and will probably be wearing callipers. About 10% will be permanently in a wheelchair, but others may use a wheelchair for most of the time, but will be able to walk a little. Few will have normal renal tracts ... and there will be many with renal diversions. In most cases the hydrocephalus will be well controlled, but as the children approach school age it may still be necessary for revision operations on the ventriculocaval shunt ... it is likely that between two-thirds

> and three-quarters of them will have an intelligence quotient within the normal range, and from this point of view be capable of receiving normal education.

Zachary, R.B., "Ethical and Social Aspects of Treatment of Spina Bifida", op. cit., supra, n.328, at p.274.

340. See, R.B. Zachary, op. cit., supra, n.335, at p.1462.

341. See, R.B. Zachary, op. cit., supra, n.331, at p.869. He writes in part, "McCormick emphasised that absolute rules about specific cases are completely impracticable, but he did suggest guidelines and I find that I agree with these, and that they form a basis on which I have formed judgments...".

342. See, S.F. Spicker and J.R. Raye, op. cit., supra, n. 290, at p.206; P. Ramsey, Ethics at the Edges of Life, op. cit., supra, n.13, at p.185.

343. Zachary, R.B., "Ethical and Social Aspects of Treatment of Spina Bifida", op. cit., supra, n.328, at p.274.

344. At the same time, Zachary maintains as do some other pediatricians, that there is more involved than only burdens: "Just because a child is seriously handicapped this does not mean that his life and that of his family are going to be devoid of happiness. Handicap is not synonymous with unhappiness." Zachary, R.B., "Spina Bifida: To Treat or Not to Treat - Give Every Baby A Chance", op. cit., supra, n.338, at p.19.

345. Zachary, R.B., "Ethical and Social Aspects of Treatment of Spina Bifida", op. cit., supra, n.328, at p.275.

346. Id., at p.274.

347. Zachary, R.B., op. cit., supra, n.331, at p.869.

348. See for instance R.B. Zachary, "Ethical and Social Aspects of Treatment of Spina Bifida", op. cit., supra, n.328, at p.275.

349. Supra, p.205.

350. Supra, n.335.

351. Supra, p.205.

352. Ibid.

353. Supra, pp.265ff.

354. Supra, pp.177-179; 224-226.

355. Supra, p.227. See also p.218. Similar results are provided by the Shaw survey. See supra, p.228.

356. Supra, p.228.

357. Supra, pp.228-230.

358. Supra, pp.182a-182b.

359. Supra, pp.201-204; 246-248.

360. See, Freeman, "Ethics and the Decision Making Process for Defective Children", op. cit., supra, n.306, at p.37. Freeman writes in part, "It appears that ethics is not a decision making field. I gather that it is far more concerned with process than with outcome. When I present ethicists a specific instance such as we are discussing today, they invariably say that it is my decision - not theirs."

361. Supra, p.96 and notes 95, 96.

362. Supra, pp.108-110.

363. Fletcher, Joseph, "Pediatric Euthanasia: The Ethics of Selective Treatment for Spina Bifida", in, C.A. Swinyard (ed.), Decision Making and the Defective Newborn, Charles C. Thomas, Springfield, Ill., 1978, at pp.477, 478.

364. Id., at p.479.

365. see, supra, pp. 75-82.

366. Fletcher himself writes, "Leaving aside the theological overtones or undertones of 'sanctity of life', most of us - even theologians - are ready to acknowledge that the survival of particular human individuals is not an absolute good". Op. cit., supra, n.363, at p.479.

367. Fletcher, J., op. cit., supra, n.363, at p.483.

368. See, J. Fletcher, op. cit., supra, n.104, p.674.

369. See , J. Fletcher, op. cit., supra, n.93, p.12. See generally on the predominance of needs over rights in Fletcher's ethics, his Situation Ethics, (14th printing), Westminster Press, Philadelphia, 1974.

370. Fletcher J., op. cit., supra, n.363, at p.482.

371. Id., at p.474.

372. On Fletcher's views about active euthanasia, see, for example his Morals and Medicine, Princeton U. Press, Princeton, 1954; "Elective Death", in E.F. Torrey (ed.) Ethical Issues in Medicine, Little, Brown, Boston, 1968, "Ethics and Euthanasia", op. cit., supra, n.104.

373. See supra, pp.97-98.

374. Fletcher, J., "Medicine and the Nature of Man", in Science Medicine and Man, Pergamon Press, 1973, 93 at p.96.

375. Fletcher, J., op. cit., supra, n.363, at p.481.

376. Fletcher J., supra, n.99.

377. See J. Fletcher, "Medicine and the Nature of Man", in R.M. Veatch and C. Morgan (eds.), The Teaching of Medical Ethics, Institute of Society, Ethics and the Life Sciences, Hastings-on-Hudson, New York, 1973, 47; "The Right to Die: A Theologian Comments", (1968) 221 Atlantic Monthly 62.

378. See, supra, p.98.

379. He writes for instance that in such decisions two factors should be considered, "...First, what are the medical facts, diagnoses and prognoses; and second, what are the personal-social factors as to the family and its psychologic and cultural resources". Op. cit., supra, n.363, at p.483.

380. Id., at p.484.

381. See, supra, p.334.

382. See, supra, p.110 and n.129.

383. It should be noted that some years after his original articles in 1972 and 1974 on indicators of humanhood, Fletcher seems to have acknowledged that certainty in these matters may be harder to achieve than he once thought. Referring to policies such as Lorber's, he wrote in 1978: "But it will have to be rigorously (and humbly) scrutinized and revamped constantly. Data on neurologic deficits and infections, and IQ prospects, appear to be shaky." Op. cit., supra, n. 363, at p.483.

384. See, supra, p.334.

385. See, supra, pp.183-186.

386. McCormick, R., "To Save or Let Die: The Dilemma of Modern Medicine", in, op. cit., supra, n.77, at p.345. For the full quote, see supra, p.78.

387. McCormick, R., "The Quality of Life, The Sanctity of Life", (1978) 8:1 Hastings Center Report, 30, at p.35.

388. Thielicke, Helmut, op. cit., supra, n.82, quoted by R. McCormick, op. cit., supra, n.69, at p.10. McCormick acknowledges that, "... the peculiar temptation of a technologically advanced culture such as ours is to view and treat persons functionally".

389. See R. McCormick, op. cit., supra, n.387, at p.34.

390. Id., p.35.

391. His normative approach has also been described as "religious consequentialism" or "personalistic utilitarianism" (by Reich, <u>op. cit.</u>, <u>supra</u>, n.232, at p.503) or as "multi-value consequentialism" (by Ramsey, <u>op. cit.</u>, <u>supra</u>, n.13, at p.180). But in our view they are wrong to focus only on the consequentialist dimension of McCormick's policy. Considered in context, his insistence upon the normative and limiting role of the sanctity of life principle makes his approach more accurately one which is deontological with exceptions on the basis of personalistic consequentialism.

392. McCormick, R., <u>op. cit.</u>, <u>supra</u>, n.386, at p.345.

393. McCormick, R., <u>op. cit.</u>, <u>supra</u>, n.69, p.13.

394. <u>Id.</u>, at p.11

395. For what follows in this and the next paragraph, see R. McCormick. <u>op. cit.</u>, <u>supra</u>, n.386, pp.348-351.

396. McCormick at this point borrows the terminology and thinking of Pope Puis XII in his talk to physicians delivered in 1957 on the subject of ordinary and extraordinary means to preserve life. Pope Puis said in part: "A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult to attain. Life, death, all temporal activities are in fact subordinated to spiritual ends". Pope Puis XII, <u>Acta Apostolica Sedis</u>, 49 (1957), 1,031-32.

397. McCormick eloquently argues in this regard: "Any discussion of this problem would be incomplete if it did not repeatedly stress that it is the pride of the Judeo-Christian tradition that the weak and defenceless, the powerless and unwanted, those whose grasp on the goods of life is most fragile - that is those whose potential is real but reduced - are cherished and protected as our neighbour in greatest need". <u>Id.</u>, at p.351.

398. McCormick actually prefers the expressions "reasonable/unreasonable" to "ordinary/extraordinary". He feels that the terms "ordinary/extraordinary" are too ambiguous and too likely to suggest "usualness". He prefers "reasonable/unreasonable" because they point

to the crucial factor of the judgment of the reasonable person as confirming (not constituting) a good moral decision. See, R. McCormick. op. cit., supra, n.387, at p.35.

399. Id., at p.36.

400. McCormick, R., op. cit., supra, n.386, at p.349.

401. See on this point and others addressed here, Warren T. Reich, op. cit., supra. n.232, at p.503.

402. Is McCormick promoting or assuming a dualistic concept of man by equating relational potentiality with the "higher more important good" and the "spiritual ends" referred to by Pope Puis XII (see supra, n.395), and then arguing in effect that physical life must be preserved only insofar as it permits the attaining of that spiritual end, that higher good? Some have seen dualism here (for example, Reich, op. cit., supra, n.400, at p.504), and it must be acknowledged that McCormick's formulation does invite that criticism by borrowing the Pope's terminology and referring to relational potentiality as "spiritual". Clearly dualism finds no support in Judeo-Christian theologies. And just as those theologies refer to persons as inseparable body and spirit in general, so too in their relationships. Human relationships are not normally referred to as "spiritual". They involve the whole person, not just the spirit or just the body. That being so, it is neither accurate nor necessary for McCormick to refer to the potential for human relationship as "spiritual" to make his point that its presence is a quality of life condition for treatment.

402a. To question as we do the use of relational potential as the primary treatment criterion is not to deny its importance, or to imply that it does not to a very large extent characterize what human life is; nor does it necessitate a return to the fallacy of vitalism. If one could determine appropriate biological symptoms to measure degrees of relational potential, it would be more arguable as a primary treatment criterion. McCormick himself acknowledges the lack of such symptoms. See, supra, pp.352-353 and note 400.

403. See R. McCormick, op. cit., supra, n.386, p.340.

404. Id., p.350.

405. See especially his, "The Quality of Life, The Sanctity of Life", op. cit., supra, n.387. In that article he compares his views to those of the following: Paul Ramsey, Robert Veatch, Bernard Haring, Albert Jonsen, Michael Garland, and Leonard Weber.

406. It should be noted in passing that Ramsey's writings tend to be extremely convoluted and to frequently lack continuity and clear logical developments. He adopts a more or less conversational style, including frequent asides, back-tracking, after-thoughts and repetition. While endearing in conversation, those same features carried to excess in writing make it difficult to always discern his real positions and policy. As well, some of his fine distinctions and objections to the positions of others are somewhat laboured and less than convincing. As we will indicate in what follows, it is not as obvious as he claims that his policy is substantially different from that of some others, for instance that of McCormick.

407. Ramsey, Paul, op. cit., supra, n.83.

408. Ramsey, Paul, op. cit., supra, n.13, at p.157.

409. Id., at p.155.

410. Id., at p.154.

411. Id., at p.159.

412. Id., at p.177.

Ramsey goes on to observe that:

> ... letting die is a justifiable, even commendable, alternative for the dying, but ... this requires no comparison of patient-persons or of different stages or conditions of the same patient-person in order to determine the quality-of-life struggles or prospects. It requires simply a comparison of treatments to determine whether any are likely to be beneficial in any way other than prolonging dying (which is of no benefit to unaware patients...). Id., at p.178.

413. Id., at p.185.

Interestingly, however, Zachary himself thinks his policy is very close to and is supported by McCormick's position. He writes about McCormick that, "... he did suggest guidelines and I find that I agree with these, and that they form a basis on which I have formed judgments. He suggests that if a newborn baby is judged to have the potential for developing human relationships then we should offer every help we can. I believe that this was the case of the mongol baby with duodenal atresia...". See, R.B. Zachary, op. cit., supra, n.331, at p.869.

414. Id., at pp.191-192.

415. Id., at p.195.

416. Id., at p.201.

417. Id., at p.205.

418. Ibid.

419. Id., at p.207.

420. Supra, p.287.

421. See, supra, pp. 199-200.

422. McCormick, R., op. cit., supra, n.387, pp.31-32.

423. Id., p.35.

424. Ramsey, Paul, op. cit., supra, n.13, pp.212-214.

425. Ramsey writes (id., at p.213): "If we use here at the beginning of life the same physiological signs of the difference between life and death which we use at the end of life, an anencephalic baby does not have the unitary function of major organ systems within which the brain has primacy".

426. Id., at p.215.

427. Id., at p.218.

428. Id., at pp.218-219.

429. Maguire, D., "Correspondence", (Oct. 6, 1972) Commonwealth, pp.3-4.

430. McCormick, Richard A., "Notes on Moral Theology", (April-September, 1972) 34 <u>Theological Studies</u> 68. McCormick bases himself largely on Helmut Thielicke, "The Doctor as Judge of Who Shall Live and Who Shall Die", in K. Vaux, (ed.), <u>Who Shall Live?</u>, Fortress Press, Philadelphia, 1970, 147.

431. Jonas, Hans, <u>Philosophical Essays</u>, Prentice-Hall, Inc., Englewood Cliffs, N.J., 1974, 105.

432. Ramsey, Paul, <u>op. cit.</u>, <u>supra</u>, n.13, at p.223.

433. <u>Id</u>., pp.202-203.

Ramsey is in total disagreement with Duff and Campbell about the ability of parents, faced with the prospect of heavy burdens of care to make a morally sensitive decision about the care of their newborn child. He refers in this regard to the Jewish teaching that only disinterested parties may take any action, even prayer, which might lead to premature death.

434. <u>Id</u>., pp.197-198.

435. For instance this statement: "... I'd rather be charged with morally justifying first degree murder in the limited circumstances I described ... than to add a feather's weight on the balance in favor of quality-of-life-judgments". <u>Id</u>., at p.225.

436. <u>Id</u>., at p.203.

437. Jonsen, Albert R., and Garland, Michael J., <u>Ethics of Newborn Intensive Care</u>, Health Policy Program, U. of California, San Francisco, and Institute of Governmental Studies, U. of California, Berkeley, 1976.

438. Jonsen, Albert R. and Garland, Michael J,, "Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal", (1975) 55 <u>Pediatrics</u>, 756.

439. Foreword, <u>op. cit.</u>, <u>supra</u>, n.437, at p.xiii.

440. Jonsen, Albert R., <u>op. cit.</u>, <u>supra</u>, n.438, at p.761.

441. Ramsey (<u>op. cit</u>., <u>supra</u>, n.13, at p.238) makes a similar observation on this point:

> Clearly McCormick's position was misused and abused in this summary of this conference's determinations; yet his language was invoked, and his standard of minimal personal interrelatedness was used - and then abused by vast extension. ... Abuse of an ethicist's position, I well know, is no argument against it. Still I think it is fair to ask McCormick to recognize the enormity of the task of containing his standard, which already is racing through medical ethical deliberations today.

442. Jonsen, A., <u>op. cit</u>., <u>supra</u>, n.438, p.762.

443. <u>Id</u>., at p.763.

444. One participant agreed to the killing of such an infant:

> If the parents administered the syringe of KCl prepared by the judge, with all the lawyers, priests, economists, psychologists and journalists within a 50-mile radius as witnesses, and no physicians, nurses or medical or nursing students were allowed to be present. <u>Id</u>., at p.767

445. <u>Id</u>., at p.762.

446. <u>Id</u>., at p.760.

447. It is true that ethical proposition four does provide that, "The State has an interest in the proper fulfillment of responsibilities and duties regarding the well-being of the infant...", but nothing is said about what specifically those responsibilities and duties are. In fact the commentary on this proposition goes on to ensure that the State does not defend the well-being of the infant too strenuously by adding: "If promotion of the child's well-being unavoidably jeopardizes other equally worthy endeavors, a reconciliation of the competing interests must be sought". <u>Id</u>., at p.761. When the life or health of a disabled infant are at stake, it would be interesting to know what exactly would be those "equally worthy endeavors".

448. See, Basil Mitchell, Law, Morality and Religion, Oxford U. Press, 1970.

449. See, Albert R. Jonsen and Michael J. Garland, "A Moral Policy for Life/Death Decisions in the Intensive Care Nursery", in, A.R. Jonsen and M.J. Garland (eds.), Ethics of Newborn Intensive Care, op. cit., supra, n.437, at p.151. It should be noted, however, that their rejection of euthanasia is not necessarily absolute or permanent, and may well be more on pragmatic grounds than grounds of principle and morality. They write in part: "Unless forms of due process can be devised to contain the practice [of active euthanasia] and give absolute protection to the rights of all vulnerable, voiceless and 'useless' members of society, it seems foolhardy and dangerous to urge a policy of active euthanasia for dying neonates".

450. Jonsen, Albert R. and Garland, Michael J., op. cit., supra, n.438, at p.762. They do go on to write, "The formulation of this principle allows for the opinion that the moral value of the infant represents a sanctity against which no lethal action can be judged ethical". [Emphasis added]. But the use of "allows for" and "opinion" hardly suggests a vigorous defence of a strongly held conviction.

451. Id., at p.760.

452. This writer has elsewhere argued that same point with regard to the use of "active" and "passive" euthanasia in the bioethical context. See, E.W. Keyserlingk, Sanctity of Life or Quality of Life in the Context of Ethics, Medicine and Law, Law Reform Commission of Canada, Ottawa, 1979, 120-129. See also, supra, n.103.

453. See, R. v. Cyrenne, Cyrenne and Cramb, (1981) 62 C.C.C. (2d) 238 (Ont. Dist. Ct.).

454. The third form of homicide in our Criminal Code is infanticide, but that is not likely to be at issue in the context of interest to us. To prove the very specific offence of infanticide, the accused must be a woman, and one who kills her newly born child in a moment of mental disturbance when not yet fully recovered from the effects of giving birth.

455. See, supra, pp.250-252.

456. See for instance Tooley and Warner. See, supra, p.251 and notes 272, 273.

457. R. v. Brooks, (1902), 5 C.C.C. 372 (B.C.S.C.).

458. See, Law Reform Commission of Canada, Euthanasia, Aiding Suicide and Cessation of Treatment, Working Paper No. 28, Ottawa, 1982, p.15.

459. Robertson, John A., "Legal Issues in Nontreatment of Defective Newborns", in, Chester A. Swinyard (ed.), Decision Making and the Defective Newborn, Charles C. Thomas, Springfield, Ill., 1978, 359, at p.362.

Robertson suggests two additional reasons why the physician's legal obligations to the infant would continue despite parental wishes. One is based on the law of contract. He writes in this regard (p.361):

> The attending physician has contracted with the parents to provide care for a third party, the infant. Ordinarily the contract for services will be ... to provide all necessary medical care. Once the child is born this contractual obligation to provide services attaches. Under the law of third party beneficiary contracts, the parties contracting for services to another cannot rescind or terminate the obligation to a minor where the minor would be thereby substantially harmed. Since the parents are powerless to terminate the physician's obligation to care for the child, the physician would have a legal duty to take such steps as are necessary to protect the interests of the child.

A second additional reason suggested by Robertson for the continuing duty of the physician despite parental refusal, is based on the fact that the physician, by informing the parents of the handicapped state of their child, has placed the child in peril. But a person who places another in peril, even innocently, incurs the legal duty to protect that now endangered person (p.362).

460. Law Reform Commission of Canada, <u>op. cit.</u>, <u>supra</u>, n.458, pp.11, 70-71.

461. See, Robertson, John A., <u>op. cit.</u>, <u>supra</u>, n.459, p.365. See also, <u>Commonwealth v. Noxon</u>, 66 N.E. 2d 814 (Mass., 1946); <u>Repouille v. United States</u>, 165 F. 2d 152 (2d Cir. 1947).

462. See, Helen Picard, <u>Legal Liability of Doctors and Hospitals in Canada</u>, Carswell, Toronto, 1978, at p.298.

463. <u>Barber v. Superior Court</u>, 147 Cal. App. 3d 1006; Cal. Rptr. [Oct., 1983].

464. In so concluding, the judge appears to have been persuaded by the testimony of one of the witnesses, Dr. Milton Tannenbein. See <u>Transcript</u>, <u>op. cit.</u>, <u>supra</u>, n.266, at p.534. But another witness, Dr. Stuart MacLeod, testified that there was at least a 95 percent probability that the morphine was the major cause of death. See, <u>Transcript</u>, at p.639.

465. This point is made and discussed by Bernard M. Dickens, <u>Medico-Legal Aspects of Family Law</u>, Butterworths, Toronto, 1979, p.105.

466. The Taschuk case may be a good illustration. The baby died in October, hospital and medical authorities only learned of the facts in late February, at which point the College suspended the physician's licence. Only in May did the Attorney General's Department make it public and admit it was considering legal action. See, "Grief Prompted MD's Mercy-Killing of Infant", <u>Ottawa Citizen</u>, May 26, 1983.

467. See for example, Robertson, <u>op. cit.</u>, <u>supra</u>, n.459, at p.366.

468. See, Law Reform Commission of Canada, <u>op. cit.</u>, <u>supra</u>, n.458, pp.15-20.

469. That standard stands out clearly for example in section 198 of the Criminal Code:

> Everyone who undertakes to administer surgical or medical treatment to another person or to do any other lawful acts that may endanger the life of another person is, except in cases of necessity, under a legal duty to have and to use <u>reasonable</u> knowledge, skill and care in so doing.

Section 45 of the Code also underlines that same standard and criterion of the reasonableness of the act under the circumstances, in protecting from criminal liability anyone who performs a surgical operation upon any person for the benefit of that person when, "it is reasonable to perform the operation, having regard to the state of health of the person at the time the operation is performed, and to all the circumstances of the case".

470. The Law Reform Commission of Canada has proposed some amendments to the Criminal Code with a view to removing that ambiguity. One such proposal is the addition of a clause which would provide that nothing in the present Code should be interpreted as requiring a physician, "to continue to administer or to undertake medical treatment, when such treatment has become therapeutically useless in the circumstances and is not in the best interests of the person for whom it is intended". See, Law Reform Commission of Canada, Euthanasia, Aiding Suicide and Cessation of Treatment, Report No. 20, Ottawa, 1983.

471. Robertson, John A., "Substantive Criteria and Procedures in Withholding Care From Defective Newborns", in Stuart F. Spicker, et al., The Law-Medicine Relation: A Philosophical Exploration, D. Reidel Pub. Co., Boston, 1981, 217, at p.222.

472. In the Matter of Quinlan, (1976) 355 A 2d 647 (N.J. Sup. Ct.).

473. Id., at p.667.

474. Id., at p.669.

475. In the Matter of B (A Minor), W.L.R. 1421 (1981).

476. Id., at p.1424.

477. Ibid.

478. In the Matter of S.D., (1983), 42 B.C.L.R. 173 (B.C.S.C.).

479. In the Matter of S.D., (1983) 42 B.C.L.R. 153 (B.C. Prov. Ct.).

480. Op. cit., supra, n.478, at p.187.

481. Id., at p.184.

That general principle is confirmed by the legal writer, John Robertson, who writes about similar cases that, "the perspective of the healthy, normal individual is the wrong perspective to take here. The view of ordinary people who know ordinary capacities for experience and interaction, and who may view the infant's existence as a fate worse than death, does not tell us how the infant who has no other life experience would view it. For him, life in a severely disabled form would seem better than no life at all, even if his life is lived in a custodial ward of a state institution." Op. cit., supra, n.470, at p.218.

482. Id., at p.183.

483. Id., at p.184.

484. Id., at p.186.

There have of course been commentaries critical of the Dawson decision. But in this writer's view those commentators have either misunderstood the medical testimony and/or legal reasons, or they give more weight to parental wishes than is in our view justified. See for example, E.-H. W. Kluge, "In the Matter of Stephen Dawson: Right v. Duty of Health Care", (1983) 129 Canadian Medical Association Journal, 815. For a reply to Kluge, see, Robert H. Hill. "In the Matter of Stephen Dawson", (Letter to Editor), (1983) 130 Canadian Medical Association Journal, 336.

485. In the Matter of Phillip B., 156 Cal. Rptr. 48, 1st App. Dist., Division 4, 1979.

486. See, George J. Annas, "Denying the Rights of the Retarded: the Phillip Becker Case", 1979 (9:6) Hastings Center Report, 18, 19-20.

487. Will, George, F., "The Case of Phillip Becker", (April 14, 1980) Newsweek, 112.

488. For example, Ontario's Child Welfare Act provides that a child in need of protection means a child under 16 years of age when the person in charge of that child:

> Neglects or refuses to provide or obtain proper medical, surgical or other recognized remedial care or treatment necessary for the child's health or well being, or refuses to permit such care or treatment to be supplied to the child when it is recommended by a legally qualified medical practitioner.

489. In the Matter of B., supra, n.475, at p.1423.

490. Robertson, John A., op. cit., supra, n.459, at p.377.

491. Task Force on Human Life, Anglican Church of Canada (Lawrence Whytehead and Paul Chidwick, editors), Dying - Considerations Concerning the Passage From Life to Death, Anglican Book Centre, Toronto, 1980.

492. In the words of the ethicist Warren Reich, (op. cit., supra, n.232, at p.495):

> Great care is needed in the use of the term "rights". No one would doubt that in many cases the child's right to life conflicts with the interests, claims or needs of the parents; but it can be misleading to refer to every interest or claim as a right, thus giving the impression that the conflict between the child's and parents' interests is between roughly equivalent claims.

493. For example, the decision in Maine Medical Centre v. Howle, No. 74-145 (S. Ct. Maine, February 14, 1974) held that:

> At the moment of live birth there does exist a human being entitled to the fullest protection of the law. The most basic right enjoyed by every human being is the right to life itself ... Being satisfied that corrective surgery is medically necessary and medically feasible, the court finds that the defendants herein have no right to withhold such treatment and that to do so constitutes neglect in the legal sense.

494. An example of this route was the set of rules issued by the (U.S.) Department of Health and Human Services (usually referred to as the "Infant Doe Regulations"), Non-discrimination on the Basis of Handicap, 48 Fed. Reg. 30, 846 (1983). They were issued as a result of much publicity surrounding the birth of a seriously disabled girl with spina bifida and other disorders, whose parents declined to consent to surgery. There were fears that many newborns were being allowed to die who should be treated. The rules have been the object of both praise and criticism. See for example, Bonnie Steinbock, "Baby Jane Doe in the Courts", (1984) 14 The Hastings Center Report, 13; John Paris and Anne Fletcher, "Infant Doe Regulations and the Absolute Requirement to Use Nourishment and Fluids for the Dying Infant", (1983) 11 Law, Medicine and Health Care, 210; Committee on the Legal and Ethical Aspects of Health Care for Children (American Society of Law and Medicine), "Comments and Recommendations on the 'Infant Doe' Proposed Regulations", (1983) 11 Law, Medicine and Health Care, 203.

495. An example of guidelines proposed by a national commission are those published by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment, U.S. Govt. Printing Office, Washington, D.C., 1983, 197-229. For a review of this generally excellent Report, see Edward W. Keyserlingk, "Review of a Report: Deciding to Forego Life-Sustaining Treatment", (1984) 4:4 Health Law in Canada, 103-107.

496. One physician expressed this point very clearly:

> I'm very much involved in making sure that habilitation and rehabilitation of spina bifida individuals is advancing, because that is really the hope. If ... I have preserved a thousand children who are going to sit in wheelchairs in nursing homes with normal intelligence ... if that's what I've done, I've created a nightmare.

McLone, David, Interview on Sunday Morning (transcript) CBS Network, August 29, 1982, at p.25 (quoted by President's Commission, op. cit., supra, n.495, at p.229).

497. The ethicist Robert Veatch expressed the point well in his, "The Technical Criteria Fallacy", (1977) 7 Hastings Center Report, 15:

> The decision [to treat or not] must also include evaluation of the meaning of existence with varying impairments. Great variation exists about these essentially evaluative elements among parents, physicians, and policy makers. It must be an open question whether these variations in evaluation are among the relevant factors to consider in making a treatment decision. When Lorber uses the phrase, "contraindications to active therapy", he is medicalizing what are really value choices.

498. For instance by The President's Commission, op. cit., supra, n.495, pp.224-228; The Committee on the Legal and Ethical Aspects of Health Care for Children, American Society of Law and Medicine, op. cit., supra, n.494, p.204; the "Infant Doe Regulations" of the Dept. of Health and Human Services, op. cit., supra, n.494.

499. President's Commission, op. cit., supra, n.495, p.227.

500. See Paul Ramsey, "The Nature of Medical Ethics", supra, n.14, pp.124-125.

501. Dr. Norman Fost spoke to this point in his testimony at the 16th meeting of the President's Commission in 1982. See, President's Commission, op. cit., supra, n.495, at p.223:

> When the [parents] begin to hear both points of view - sometimes it's only that there are excellent adoptive homes for such kids - that's often never raised - that changes the decision. Sometimes they just need to learn more about Down's. Parents have such horrible fantasies about it; it's mongolism and it's something monstrous, they think. This wider process is often nothing more exotic than bringing facts into the discussion.

502. See, President's Commission, op. cit., supra, n.495, pp.217-223.

503. Examples suggested by the Report of the President's Commission, op. cit., supra, n.495, p.220, are, "... a child with a debilitating and painful disease who might live with therapy, but only for a year or so, or a respirator-dependent premature infant whose long-term prognosis becomes bleaker with each passing day".

504. The "Infant Doe" Regulations, (op. cit., supra, n.494) for example, state:

> ... the basic provision of nourishment, fluids and routine nursing care is a fundamental matter of human dignity, not an option for medical judgment. Even if a handicapped infant faces imminent and unavoidable death, no health care provider should take it upon himself to cause death by starvation or dehydration.

For cogent objections to such a rigid rule, see, J. Paris and A. Fletcher, op. cit., supra, n.494.

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