

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

## Chapter 5

### Treating and Dying

#### A. “Ordinary Means”, or “Reasonable Treatment”?

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

##### 1. The meanings of “Ordinary/Extraordinary”

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

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

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

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

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

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

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

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

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

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

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

*American Medical Association (1973):*

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

*Canadian Medical Association (1975):*

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

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

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

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

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

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

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

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

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

medical means — repugnance of the procedure itself, cost, abhorrence of the social consequences such as separation from one's family, and the like. On the other hand, certain procedures might be useless to save or even to prolong the life of a patient, but could nevertheless be imperative for the patient's comfort.<sup>1157</sup>

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

## 2. The “Reasonable Person” Standard

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

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

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

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

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

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

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

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

### 3. Language or Substance

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

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

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

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

## B. Euthanasia or Allowing to Die with Care?

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

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

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

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

*(Major premise):*

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

*(Minor premise):*

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

*(Conclusion):*

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

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

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

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

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

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

#### 1. The Problem of Language — Euthanasia as “Killing”, not “Allowing to die”

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

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

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

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Now Smith killed the child, whereas Jones “merely” let the child die. That is the only difference between them.<sup>181</sup>

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

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

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

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

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

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

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

### 3. On Maintaining the Distinction

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

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

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

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

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

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

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

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

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

in this area of whether a code would be weakened or strengthened by the addition of active euthanasia principles.”<sup>190</sup>

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

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

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

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

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

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

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

#### 4. Some Possible Exceptions?

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

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



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

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

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

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

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

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

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

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

### C. Conclusions: Refusing Treatment and Causing Death

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

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

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

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

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

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

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

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

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

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

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

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

— Johannes Maria  
Simmel

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

— de Tocqueville

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

— David Mechanic

## Chapter 6

# Rights and Responsibility in Ethics, Law and Medicine

### A. Utility of the Rights Model, the Law Model

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

#### 1. The “Who Decides”, “Who Controls” Question

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

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

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

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

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

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

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

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

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

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

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

## 2. Rights in Medical Ethics. Some Opinions

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



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

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

These views do not adequately recognize that for some purposes and contexts the rights approach might be useful and essential, even though inappropriate or at least insufficient in others. As well, they have an "either/or" flavour to them which this writer does not share. Let us now attempt to push the analysis a little deeper, in an attempt to sort out and evaluate the pros and cons of the rights and law models when used in ethical reasoning and policy-making. For much of what follows we are indebted to the analyses of John Ladd<sup>201</sup> on the ethic of rights, the ethic of responsibility and the notion of "ideal rights".

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

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

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

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

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

#### 4. Coping with Impersonal Relationships and “Public Rules”

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

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

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

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

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

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

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

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

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

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

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

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

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

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

### 1. Rights as Peremptory, Adversarial and Minimal

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

## C. An Ethic of Responsibility

### 1. A Comparison with an Ethic of Rights

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

## 2. Its Relevance for Law Making and Health Care

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Aided by his legally encouraged detachment and objectivity,

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

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

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

## D. The Notion of “Ideal Rights”

### 1. Ideal Rights as Non Proprietary

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

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

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

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

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

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

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

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

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

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

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



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

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

## E. Conclusions: Rights, Responsibility and Quality of Life

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

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

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

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

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

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

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

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

## PART III

### SOME RECENT PUBLIC POLICY GUIDELINES AND PROPOSALS – HOW THEY MEASURE UP

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

## Chapter 7

### Hospital Guidelines for the Terminally Ill

I will refer to only two of the several such guidelines proposed recently. One is the set of guidelines drawn up by a group from Beth Israel Hospital in Boston, and the other was drawn up for the Massachusetts General Hospital, also in Boston, both in 1976.<sup>221</sup>

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

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

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

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

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

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

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

One is left equally uneasy when it comes to the *incompetent* patient in these guidelines. For reasons already referred to earlier, parents are the most appropriate decision-makers for minors, and other family members (or guardians) for incompetent adults. Karen Quinlan's father for instance was judged by the court to be her most appropriate guardian. But in these guidelines all these people are more or less excluded from decision-making. The Beth Israel guidelines do include them, but one is left uncertain as to whether the review committee or the family would prevail should there be a disagreement.

Is the patient's perspective primary in these guidelines? One fears not — at least not primary enough. What compromises that perspective somewhat is the blurring of the distinction between the medical and the moral dimensions in these decisions to cease treatment. Both are important, but, “. . . the decision to terminate or continue treatment is basically a moral or religious one. . . By emphasizing the role of the physician as decision-maker, with the family as legitimating or acquiescing body to what is conceived as basically a medical decision, this distinction is lost. And when it is, the primacy of the patient's interest is negated.”<sup>225</sup>

Particularly in the case of the Massachusetts General guideline, one has the impression that the primary goal of the guidelines was the achievement of greater staff unity and mutual support, a very worthy goal. But it should not be the primary goal, nor should it be assumed that if such unity and standardization is achieved that will in itself, and inevitably, ensure the promotion of the interests and benefits of patients. “Guidelines can be useful if they are intended to provide a means by which patients and families can obtain information, make decisions, and ensure that their decisions are respected. But if they are primarily intended to reinforce the authority of the physician and to allow the patient and family at best a consultative role, they serve only to legitimate the physician's traditional paternalistic role and minimize the patient's autonomy.”<sup>226</sup>

There is of course another side, another view, which deserves to be heard as well. It is a view with which one should have some sympathy, namely that the very introduction of guidelines and committees might only further complicate and institutionalize an

exceedingly sensitive and personal experience already too depersonalized and bureaucratized. The same hesitation was expressed earlier in this paper in the discussion of rights. One (perhaps too strong) expression of this view is this opinion of a surgeon, "... official guidelines will benefit only lawyers and administrators, while making it infinitely more difficult for physicians to do for the dying what most of them have been doing all along."<sup>227</sup>

Agreed. Under ideal conditions, assuming personal relationships between physicians and patients, assuming the physician knew beforehand the wishes and values of his comatose patient, and assuming the patient knew the physician's values and treatment policies, then guidelines and committees (just as the resort to the claiming of rights) would not be as necessary. But given the impersonality of many patient/physician, patient/staff relationships, as well as the variety and unpredictability (from the patient's point of view) of individual physicians' cessation of treatment policies, guidelines and committees have probably become a (perhaps regrettable) necessity. But only if the patient's interests are put first can they be a step forward instead of a step backwards.

## Chapter 8

### Courts and Incompetent Patients

Let us now turn to the consideration of a recent and extremely controversial court decision, namely the “Saikewicz” decision of the Massachusetts Supreme Judicial Court.<sup>228</sup>

First of all the case facts. The patient was a seriously mentally retarded man of 67, Joseph Saikewicz. He was able to communicate only through gestures and physical contact, and had been in a state school all his life. His I.Q. was ten, and he had a mental age of approximately three years. He was diagnosed as terminally ill with leukemia, but not in pain. The only treatment known to be effective is chemotherapy, which offered only a 30 to 50 percent chance of remission for a duration of from 2 to 13 months. The pain and other side effects of the treatment would be severe, the patient would be unable to understand what was happening to him, would not be able to cooperate in the treatment and might even need restraint. The school was unsure of what to do, and his only relatives (two sisters) did not want to become involved.

The superintendent of the school therefore petitioned the Probate Court for a guardian to be appointed, which the judge did. The guardian recommended that treatment would not be in the patient's interest, and the Court agreed. The grounds for the decision were essentially, the patient's age, the side effects, the inability to cooperate with treatment, the low likelihood of remission, the pain, and the quality of life possible after a remission. The decision was appealed, and the Supreme Judicial Court affirmed the



decision, adding that a full opinion would follow later. In the meantime Saikewicz died peacefully and painlessly of pneumonia. A few months later the Court's full opinion followed (in Nov. 1977).

The opinion dealt essentially with three points. They are: the *right of anyone*, competent or incompetent to decline potentially life-prolonging treatment; the *legal standards* controlling the decision as to whether potentially life-prolonging (but not life saving) treatment should be provided to an incompetent person; *procedures* to be followed in arriving at the decision. I will limit my comments to just a few of the many issues raised and considered by this decision, and deal with them largely from the perspective of the normative criteria argued for earlier in this paper.

First of all, the positive aspects of the decision. There are two points which (in my view) merit approval. First of all there is strong insistence by the court that both competent and incompetent patients have substantially the same right to decline potentially life-prolonging treatment. As regards *incompetent* patients this might be the clearest and strongest such assertion of patient autonomy and dignity to date.<sup>229</sup> This assertion merits unqualified approval, in view of the dignity and autonomy it recognizes in all patients.

Secondly, the court adds a (theoretically) helpful and very "patient-oriented" qualification in deciding for a more specific standard than the "reasonable person" standard in resolving cases involving incompetent patients. The court set as its goal, to "determine with as much accuracy as possible the wants and needs of the individual involved." Because it puts patient self-autonomy first, it seeks to replace the "objective" reasonable person standard with the "subjective" test of the "substituted judgment". By this test courts and juries are not to ask what reasonable persons would do in these circumstances, but what *this patient* would have done.

Applied to Saikewicz, who would not understand the pain of chemotherapy treatment, he should be compared to a *competent* person who is informed that something painful will be done for a long time for reasons he won't understand and won't be told. Applying *this* test, as the Court did, it ruled that the factors against treatment outweighed those in favour.

One can only agree that in principle and from the moral and patient-centered perspectives this position of the Court could represent a new and added sensitivity to the particular needs and benefits of individual incompetent patients. Yet two reservations

come to mind. First of all, how often is it really possible to make a reliable “substituted judgment”, especially perhaps by courts, since they tend to value so highly objectivity and detachment? Knowing what a *particular patient* would have wanted is no easy knowledge for anyone, but if anyone is likely to know, surely it is those closest to him, especially the family and sometimes the physician as well, but least likely an “objective and detached” court. But as we will see in a moment, family members are to be more or less replaced by judges in such decision-making.

But whoever is to make the “substituted judgment”, it simply is not as easy or as certain a task as the Court seems to assume. After all, even when dealing with a fully competent person, whose behavioural signs are presumably conscious and reasonably accurate translations of his wishes and experiences, these latter are seldom fully transparent to another. We can have a “more or less” idea, but each person’s way of experiencing is as unique as his personality and particular circumstances. How much more difficult still (if not impossible) is substituting judgment or “seeing things as another sees them” when it is a never-competent and non-communicative person under consideration.

Secondly, is there really that much difference in practice between the (objective) “reasonable person standard” and the (subjective) “substituted judgment test”? After all, the reasonable person standard attempts to determine what reasonable persons would do in *these circumstances*. Is that approach likely to produce a different conclusion than asking what *this patient* would have done? One wonders. Consider again the Saikewicz case. Surely one of the “circumstances” a court would (or could) weigh using the reasonable person standard is the fact that Saikewicz would not understand the pain or the reasons for the therapy, and could conclude that a *reasonable person* faced with protracted, painful, unexplained and incomprehensible therapy of doubtful success would refuse that treatment.<sup>230</sup>

Let us now consider two further positions of this court. The first concerns the court’s understanding of the meaning and role of “quality of life”. On this point the court appears to be both confusing and self-contradictory. In a rather unclear statement it asserted that, “to the extent that this formulation equates the value of life with any measure of the quality of life, we firmly reject it.” The statement seems to refer to Saikewicz’s mental retardation, and to be asserting that a mentally retarded person is worth saving. It went on to grant that it is correct to use the term “quality of life”

(as the probate court did), for the pain and discomfort which would be caused by the chemotherapy treatment.

The court's view is at least confusing in that it appears to assume that quality of life considerations (at least when they deal with patient conditions such as mental retardation) will tend most of the time to go against preserving the patient's life. Clearly, as this paper has argued, this need not be the case. Weighing *only* Saikewicz's condition or "quality" of mental retardation, one could and should conclude, with the court, that because he had at least a minimal ability to experience and relate, that quality of life test (alone) did not justify the non-initiation of treatment.

But not only does the court's formulation in this regard seem to assume the reductionist or "optimal life" meaning of quality of life in rejecting it, but it *does* in fact weigh his quality of life (i.e. mental retardation as well as pain) in deciding against treatment. It was after all partly due to his inability to cooperate with the treatment and to understand it (because seriously mentally retarded) that the "substituted judgment" test used by the court led it to conclude as it did. It therefore appears to be somewhat self-contradictory. I do not maintain that the condition of serious mental retardation *alone* argues for non-initiation of treatment, but only that (as the court itself did) it should be weighed along with the other conditions.

What is particularly unfortunate is the possible implications this assertion might have (at least in the U.S.) for medical decision-making generally when it comes to weighing similar factors. "This ruling could mean that brain damage to an infant, or very serious burns and disfigurement and limited bodily functioning, could not be taken into consideration in offering or withholding resuscitation or intensive care to a patient."<sup>231</sup>

A second point which merits disagreement (as it has by many commentators), has to do with the *procedures* proposed for resolving this kind of issue. In effect the court ruled that the question of whether to continue or withhold potentially life-prolonging treatment was for the *courts* to decide, and not any other group. The following citation well conveys both the tone and the substance of that particular ruling:

We do not view the judicial resolution of this most difficult and awesome question. . . as constituting a 'gratuitous encroachment' on the domain of medical expertise. Rather such questions of life and death seem to us to require the process of *detached but passionate investigation* and decision that forms the ideal on which the judicial

branch of government was created. Achieving this ideal is our responsibility and that of the lower court, and is not to be entrusted to any group purporting to represent the 'morality and conscience of our society', no matter how highly motivated or impressively constituted. [Emphasis added]

If one believes that law and courts should be involved in these matters only as a last resort, then obviously such a belief is diametrically opposed to the position of this court. There are three points worth noting about the decision before making a brief comment. First of all, it explicitly and substantially disagrees with the Quinlan court decision, in that the latter entrusted the decision as to whether to continue artificial life support to the patient's family, attending doctors and a hospital ethics committee. Secondly, the Court appears to reserve to itself both kinds of decisions — those which decide to initiate or continue treatment, as well as those decisions against treatment. Thirdly, it is proposing that as a *general rule*, and not just in cases of conflict, the court and no one else should make these decisions. The advice of parents and others would of course be sought and heard by courts, but it would not be decisive.

As was already argued earlier, one need not believe as does the Court, that "detached but passionate investigation and decision" of the courtroom is necessarily (at least in the first instance) the best stance from which to decide these issues. Nor need we agree with the strongly implied bias against the likelihood of families, physicians and ethics committees contributing to responsible decisions made in the interest of the patient. George Annas (a Professor of law and medicine), in commenting on the case has expressed a view similar to this court's, though still more explicit. "A correct resolution. . . is more likely to come from a judicial decision after an adversary proceeding, in which all interested parties have fully participated, bringing in all their own perceptions, beliefs, and biases, than from the individual decisions of the patient's family, the attending physician, an ethics committee, or all these combined."<sup>232</sup>

One cannot fail to note in that view the assumption already noted above in discussing rights — that family members (and physicians) are by definition, too close, too identified with the patient, too "biased", to be capable of responsible decision making.

But another legal writer (William Curran), takes issue with the reasoning of the court and of Annas in this respect. And this for four reasons:

1. It misunderstands and mistrusts the role and ability of the medical care system to deal with these issues with both equity and sensitivity.
2. It assumes these decisions of ethical groups (or families) are not appealable to the courts when there is disagreement or suspicion of abuse. They are of course appealable.
3. Hospital committees for the most part are not really deciding ethical or legal matters — they are more aptly called “prognosis committees”, and are essentially *advisory* already.
4. The court procedure is too slow and cumbersome to use for the patient’s benefit. Delays do not mean a stable condition while the court deliberates — they mean that a decision is made *to continue* treatment — often to the detriment of the patient.<sup>233</sup>

Let us finish this point with an appropriate comment by a physician as to the likely outcome of this decision as it affects patients. Only time will tell whether his dire prediction is accurate or not.

In some cases physicians and next of kin will probably defer urgent medical decisions, both positive and negative, pending court approval. In other cases decisions that had formerly been made expeditiously, but only after full and explicit consultation, will now be made hastily and even furtively, thus returning ‘to the closet’ questions that need open and thoughtful discussion.<sup>234</sup>

## Chapter 9

### Seriously Defective Newborns

The care and treatment problems and decisions involved with intensive care of newborn infants are special, and urgent. A few years ago an interdisciplinary group, some of them with direct responsibility for newborn intensive care, formulated a "Moral Policy of Neonatal Intensive Care."<sup>235</sup>

The "Moral Policy" was formulated against the background of some much discussed, but very concrete, difficult and tragic cases, such as those infants born with spina bifida and various genetic defects, as well as the still more common cases of severely asphyxiated preterm infants with respiratory distress and in need of prolonged assisted ventilation.

The group attempted to formulate a policy which could accommodate, "the diversity of private beliefs within some degree of broad agreement about how such cases should be managed" and to mingle "statements of principle with procedure". The formulators realize the policy may seem "unreal", but (rightly) argue that, "the air of unreality is, we believe, the necessary cool moment which philosophers say should precede any reasonable judgment. That judgment will have to be made amid hard realities, but it may be better made in the light of reflections on these principles."<sup>236</sup>

The ethical propositions are the following:

- (1) Every baby born possesses a *moral value* which entitles it to the medical and social care necessary to effect its well being.

- (2) Parents bear the principal *moral responsibility* for the well-being of their newborn infant.
- (3) Physicians have the *duty* to take medical measures conducive to the well-being of the baby in proportion to their fiduciary relationships to the parents.
- (4) The State has an *interest* in the proper fulfillment of responsibilities and duties regarding the well-being of the infant, as well as an interest in ensuring an equitable apportionment of limited resources among its citizens.
- (5) The responsibility of the parents, the duty of the physician, and the interests of the State are conditioned by the medico-moral principle, "do not harm, without expecting compensating benefit for the patient".
- (6) Life-preserving intervention should be understood as doing harm to an infant who *cannot survive* infancy, or will live in *intractable pain*, or cannot participate even *minimally in human experience*.
- (7) If the court is called upon to resolve disagreement between parents and physicians about medical care, prognosis about *quality of life* for the infant should weigh heavily in the decision as to whether or not to order life-saving intervention.<sup>237</sup>
- (8) If an infant is judged beyond medical intervention, and if it is judged that its continued brief life will be marked by pain or discomfort, it is permissible to hasten death by means consonant with the moral value of the infant and the duty of the physician.
- (9) In cases of limited availability of neonatal intensive care, it is ethical to terminate therapy for an infant with poor prognosis in order to provide care for an infant with a much better prognosis.

It would take us well beyond our underlying sanctity of life/quality of life concern to attempt any detailed evaluation of the many issues raised and implied in these propositions. One can at least draw attention to the way most of these propositions reflect and articulate concerns and criteria stressed earlier in the paper. They are patient centered (see especially nos. 1, 5, 6, 8); parents have the primary decision-making responsibility (see especially nos. 2, 3); quality of life considerations are central to decision-making about life saving intervention, wherever the decision is made, including in the courts (see especially nos. 6, 7, 8); central to quality of life factors are minimal human experience and intractable pain (nos. 6, 8); it is at least implied that the court is a place of last

resort, for the resolution of “disagreement between parents and physicians about medical care” (see no. 7).

As noted above, there is an occasionally disconcerting element of vagueness and openness in one or two of the formulations. But that was intentional, and is probably more of a strength than a weakness. These propositions comprise, after all, an attempt to accommodate a wide diversity of private beliefs and are not intended to be the “last word” — rather they are proposed to stimulate debate, and be only a stage towards framing questions and priorities with more precision than usual on this subject.

One proposition which is particularly vague and open, and into which one is invited to pour one’s own view or opinion, is no. 8. But in my view it is just a little *too* vague to yet be useful for public policy purposes, especially in view of the very different positions the authors claim could live under its banner. As it stands, it appears to allow direct killing (euthanasia) in that, “. . . it is permissible to hasten death . . .” But the authors do not necessarily intend that meaning. “The morality of active euthanasia is far from settled. We do not intend to settle it here.”<sup>238</sup> The proposition is equally compatible, the authors maintain, with the “double effect doctrine”, or the distinction between “acts of commission and omission”. From the context it appears that the authors themselves might feel euthanasia is permitted, though no attempt is made to argue that view.

They do make one observation which might be intended as an argument in support of euthanasia, but is equally relevant to “allowing to die”. “We suggest that there may be a significant moral difference between an infant whose therapy has been terminated and an adult whose condition is diagnosed as hopeless. . . For the adult, the time intervening between verdict and death may be of great personal value. For the infant, the intervening time has no discernible personal value.”<sup>239</sup> This argument in other words seems to take abilities or functions not (yet) possible for newborns (i.e. *present* self-consciousness or actual ability to reason, choose and plan) as the norm of “personal value”. As such it seems very close to the kind of quality of life views this paper rejected earlier — the view which compares the worth of lives on the basis of capacities, or the one which is prepared to protect and value human life only when it achieves personhood in the “strict sense”.

And yet, if we exclude any element of comparing the worth of different lives, or any suggestion that either of those two lives in



question are not valuable to *us*, then it is no doubt true that for an adult the intervening time between “verdict” and death can have *to that adult* a discernible benefit, whereas there is no *discernible* benefit in that intervening time *to that newborn*.

## Chapter 10

### Allocation of Scarce Resources

The problem of the allocation of scarce resources is one which will never go away, despite any utopian dreams (nightmares?) of unlimited health care for everyone, and a whole variety of efforts and proposals which more or less assume that that dream is about to become reality.

Because there are in this issue some urgent moral questions about justice and equity, as well as implications for quality of life concerns, it is one which we should look at here, if only briefly. The particular criteria we will focus on were at least an attempt (largely a failure in most peoples' view) to face the reality that we cannot have everything we want by way of medical technology and resources. They are the *admission criteria* used by the *Seattle Artificial Kidney Center* until 1972.<sup>240</sup> The U.S. federal government subsequently took over financial responsibility for almost all patients needing artificial kidneys, so these criteria are in a sense history at this point. But because they did attempt to meet a real and continuing problem, and because some of the least morally justifiable aspects of those criteria continue to tempt us or to re-appear in different guises, it is never too late to look back and learn.

Of particular relevance to us here is the feature of those criteria which occasioned most of the uneasiness and opposition — namely the *social worth criteria*. There were medical criteria as well, but the *strictly* medical criteria were few — perhaps only two: a slow deterioration of renal function, and an absence of longstanding

hypertension and its permanent complications. The rest were all more or less social worth criteria such as: the patient's emotional maturity and responsibility; his demonstrated willingness to cooperate; a "physiological" age of between 17 and 50; the amount of his financial resources; his value to the community; potential for rehabilitation; psychological and psychiatric status.

The committee members were anonymous, and at one point the members were a clergyman, a housewife, a banker, a labour leader and two physicians. A physician at the Center at the time described the selection process:

There was the beatnik — in his mid-twenties, doing poorly in college (in spite of considerable effort on the part of the faculty sponsor), poor job record, and apparently without funds or plans for the future. He just did not seem to fulfill the criteria of value to the community and rehabilitation potential. There was the lady of ill repute (a veritable Camille) and although she had plenty of financial support, it was not felt that she could be considered a responsible citizen. . . A final example is the logger who seemed to qualify in every way, except that our staff and his employer simply were unable to put together any semblance of a financial package for his continued care. He expired the same day a letter of rejection and explanation went to his wife. . .<sup>241</sup>

No wonder then that one commentator wrote that the criteria and the selection process, ". . . paint a disturbing picture of the bourgeoisie sparing the bourgeoisie, of the Seattle Committee measuring persons in accordance with its own middle-class suburban value system: scouts, Sunday School, Red Cross. This rules out creative non-conformists, who rub the bourgeoisie the wrong way. . . The Pacific Northwest is no place for a Henry David Thoreau with bad kidneys".<sup>242</sup>

Clearly what we have here is the use and abuse of "quality of life" considerations, but quality of life understood in the sense this paper has consistently rejected as immoral in this context — that of relative social worth, or social value, involving a determination by others of the "worth" or "value" of people according to extrinsic, subjective and relative criteria.

One commentator has well identified the immorality of "social worth" selection criteria: ". . . we have *no way of knowing how* really and truly to estimate a man's societal worth or his worth to others or to himself. . . The *equal* right of every human being to live ought generally to prevail. . . [emphasis added]."<sup>243</sup> He goes on to write, "No one can tell the worth of an old man sitting on the porch watching a sunset, or ponder imponderables like the relative moral

worth of comparative genetic inheritances, or say whether a disturbed or seemingly undisturbed child should be saved. When tragically not all can be saved, the rule of practice must be the *equality* of one life with every other life. . . .<sup>244</sup>

How then ought we to make choices in such matters? What is the best method? The first answer is that we will never know for sure. But that does not mean we are wrong to reject "social worth". In the words of L. Fuller, "We can . . . know what is plainly unjust without committing ourselves to declare with finality what perfect justice would be like."<sup>245</sup>

Generally speaking there are four methods proposed for the selection of patients for access to scarce resources: (1) social worth; (2) selection rules based on statistical medical probabilities (*i.e.* "all persons over 40 will be excluded from hemodialysis"); (3) random selection by lottery or on the basis of "first come, first served"; (4) when not all can be saved, no one should be selected.<sup>246</sup>

As Paul Ramsey notes, there are essentially only two principles to choose between — randomness among lives presumed to be equal, and comparison of social worthiness. Only the former, ". . . would ensure equality of opportunity to live, and not die, to every one of a class of patients, and it would forbid the physician from raising questions of comparative social merit as a means of determining who lives and who dies".<sup>247</sup>

But of course none of these considerations, important as they are, have yet come to grips with (what should be but seldom is) our prior and more fundamental concern, namely the establishing in a rational manner, of social and medical priorities and needs. Questions about who should have access to scarce *existing* resources, surely should come second in time and importance to questions about how we establish our priorities about the kinds of medical technology and services we will make available, and which resources *shall be* plentiful and which scarce. As long as there will be limits to what can be provided (presumably forever), and other claims and needs competing with the medical ones, the need to establish priorities will exist. It is of course essential to establish (as we have tried to do above) the principle that everyone should have an equal opportunity of access to the existing medical resources, plans and services, but what shall they be?

It is a common and generally justified complaint that health care discussions and questions are too seldom fundamental enough, too

seldom aware of the larger and ultimately more influential (for good or ill) contexts, issues and dilemmas. Consider for example this "minority view" by one of the participants at a conference discussing newborn intensive care:

We cannot dismiss the economics of neonatal intensive care by simply stating, 'an infant is not simply a commodity whose value is defined by its utility.' Questions should be raised: Who benefits economically from neonatal intensive care? . . . Furthermore, what are the preventative possibilities, and why was this not relevant? Can the number of such (deformed) infants be reduced by monitoring drug, geneology, and environmental inputs? . . . We never pursued the question, how has our society come to be spending so much time and money on neonatal intensive care without similar attention to born healthy, but later not so healthy, deprived children — is this development related to special interests that may be ours although we are unaware of them?<sup>248</sup>

It has been suggested that as long as medical needs will exceed our resources, some form of "triage" might be a just social policy.

. . . We may have to learn not always to give the advantage to spectacular and costly treatments in ordering our priorities, if medical resources are ever to be distributed justly. This would be a form of triage, accepting the death of some of the most desperate sorts of cases in order to give the first attention to many whose needs are urgent, to be sure, but who are not yet at the end stage of some fatal illness. . . when not everything can be done that ideally should be done, it does not necessarily follow that the maximum research and personally and socially worthy medical care should be expended upon the most desperate cases first.<sup>249</sup>

Aspects of such a policy are well worth considering. But there are as well some serious problems and dangers with a policy of ordering our medical resource priorities according to a triage approach. Triage as a general policy could well turn out to be a "social worth" criterion in another guise. Two dangers in particular merit consideration. "First, common good considerations are, in practice, often disguised special interest considerations. Favoured treatment of certain persons or classes is judged, by those identified with those persons or classes, to contribute to the common good. Secondly, the hope of survival with maximal function is predicated not only on the physical potential of the infant but on the socioeconomic world into which it enters. Thus, estimates of the quality of future care may bias selection."<sup>250</sup>

But not only do we need to establish medical priorities *within* the medical field — those priorities must themselves be weighed by the *larger context of social priorities*. "To what extent ought medical needs be served in comparison to eradicating poverty,

stopping the decay of our cities, depolluting our atmosphere and streams, defending the nation, and aiding underdeveloped peoples? Again, it is quite clear that while all things are possible, all things are not compossible, as Leibnitz said.<sup>251</sup>

A major temptation to be resisted is that of making the *cost* factor the only effective and articulate criterion in establishing these priorities. If cost factors are the major or only considerations, then decisions about medical priorities tend to be ad hoc, irrational and inadequate. Just because there is X amount of money left in the hospital or Health Ministry budget is not in itself enough reason to buy this piece of medical equipment rather than that one, or to start this program as opposed to that one.

The (moral) questions are for instance: where are the *greatest needs* (and not just the loudest voices); what *norms* are the most justifiable for determining those needs and establishing priorities; *who will be served* by each option, what are the *rejected* options implied in each positive choice, and what needs or segments of society will be *less served* because of any particular choice of a service, a program or a technology; do we value and respect lives sufficiently to (sometimes drastically) *re-allocate* our (budget) priorities in order to provide humane care; should the value of life be reduced largely to *cost-benefit* analysis (too often with more emphasis on cost than on benefit).<sup>252</sup>

Whether or not we need more legislation directly addressing the issues of methods and priorities in the allocation of and access to health resources is difficult to say. But there is at least an urgent need for hospital administrators and Health Ministries to articulate and publicize the norms they use at present. Only if this is done can citizens be reassured that there are in fact such norms being used.<sup>253</sup> Only if this is done can we be reassured that "social worth" criteria have not crept in and quietly become normative in one guise or other. Only if this is done as a first step can there be a healthy public debate. If such a disclosure and debate takes place, "... it could happen we the people might learn not only the direction in which to throw tax money for medical research and the distribution of medical services, but also how as a people we should go about deciding the nation's priorities in general."<sup>254</sup>

## Chapter 11

### Natural Death/Living Will Legislation

As argued earlier, from the ethical perspective the decisive factor in treatment decisions normally ought to be patient wishes, based upon the patient's right to self-determination. This self-determination extends to determining one's own quality of life in terms of one's own mix of values such as ability to function and degree of pain, and accordingly at some point deciding to refuse treatment and be allowed to die.

But what if the patient is no longer competent, is comatose for instance? In such instances the first concern of the physician would normally be whether or not the patient orally or in writing indicated whether or not he or she wished treatment to be initiated, continued or discontinued in the event of a particular medical diagnosis and prognosis. Some sort of informal, previously written indication (in recent times often called a "living will") can be very helpful and reassuring to both patients and physicians, and an important protection and extension of patient wishes and self-determination when and if the patient is no longer able to communicate.

In my view one of the best expressions to date of such a "living will", one which incorporates many of the concerns we have considered in this paper, is that proposed by Sissela Bok:

I wish to live a full and long life, but not at all costs. If my death is near and cannot be avoided, and if I have lost the ability to interrelate with others and have no reasonable chance of regaining this ability, or if my suffering is intense and irreversible, I do not want to have my life

prolonged. I would then ask not to be subjected to surgery or resuscitation. Nor would I then wish to have life support from mechanical ventilators, intensive care services, or other life-prolonging procedures, including the administration of antibiotics and blood products. I would wish, rather, to have care which gives comfort and support, which facilitates my interaction with others to the extent that this is possible, and which brings peace.<sup>255</sup>

But ought these "living wills" to be supported *in law*? Would patient wishes, patient self-determination be given still greater protection and scope if living wills were made legal documents, supported by "natural death" legislation? In my view both the arguments supporting that move and the examples of natural death legislation and legal living wills enacted or proposed to date, suggest that patient self-determination might more likely be eroded than reinforced.

That the translation of living wills into legislation has caught on in recent years is evident. In the U.S. the trend began with the introduction of a Natural Death Act in Wisconsin in 1971. In one year alone (1976), 17 States had variations of Natural Death/Living Will Bills under consideration. In 1976 California became the first State to actually pass legislation.<sup>256</sup> In 1977, 7 States enacted Natural Death Acts, most of them using the California model with some variations. So far the only Canadian legislative proposal was a Bill entitled the *Natural Death Act* introduced as a Private Member's Bill in the Ontario Legislature in 1977. It too was loosely based on the California Act. It was given second reading, but in the face of considerable opposition from various groups as well as new reservations on the part of the Member who introduced it, it was not reintroduced after a government election.

It cannot be my purpose here to attempt a detailed description or evaluation of these Bills. It is enough to note that the features common to most of these Bills, at least the more recent ones are these:

- (1) The Bills recognize the right of adults to direct physicians to withdraw "extraordinary" life sustaining treatment in specified circumstances of terminal illness.
- (2) Terminal illness is defined as one which will result in "natural death", whether life sustaining procedures are used or not.
- (3) One becomes a patient "qualified" to so instruct one's physician once one has been diagnosed as terminal, and verified



as such by one or more physicians. There is generally a "cooling off" period specified between the diagnosis and the (valid) signing of a directive (two weeks, in California).

(4) The physician who complies, as well as the health facility, are protected from liability.

(5) In most cases, no real penalty is attached for violation.

My primary reservation about living will legislation of this kind is a general and basic one. It is one well expressed in these words:

The very fact that a law is deemed necessary to assure patients' rights implies, and therefore tends to reinforce, an erroneous presupposition about the locus of decision-making in the physician/patient relationship.<sup>257</sup>

Two points already noted or argued earlier are relevant to this issue. First of all, patients already have the right to refuse medical advice and treatment, whatever the physician might think of that refusal. Secondly, if the patient is comatose or otherwise incompetent, parents or family (not physicians or courts) in the first instance, have the responsibility and right to make decisions involving cessation of treatment. That means if a physician does not agree with a family's request about its patient-relative, the physician, not the family, should appeal to the courts.<sup>258</sup>

There are a number of reasons why laws about natural death and living wills are likely to encourage a shift in decision-making laws away from patient/family towards the physician, and to make the physician more a servant of the statute than of the patient.

The major reason is this: in defining terminal illness in a very narrow way, and in securing rights for the very small range of cases which fit the specifications of those qualified to write legally valid instructions, a "natural" right to refuse treatment in *many* situations is by implication reduced to a conferred or acquired right in this one situation. The securing of rights for *some*, risks the curtailing of rights for a much larger number. The danger is that physicians will assume that those who could have signed a directive but did not (likely the vast majority), wish vigorous and "useless" (extraordinary) treatment to continue. Insofar as this danger is real, the onus will have shifted to the patient to write such a formal directive, and away from the traditional recognition of patient wishes communicated in a less formal (even oral) manner, away from the traditional recognition of allowing patients to die for a wide range of reasons,

away from the traditional recognition of a right to refuse treatment which puts the onus of legal recourse on physicians and others who disagree, not on the patient.

The *California Natural Death Act* (Assembly Bill 3060) is a case in point. It states that only mechanical or other artificial means to restore or supplant a vital function may be withheld or withdrawn, and only when death is imminent whether or not life-sustaining procedures are used. As a result many situations in which treatment refusal is normally acceptable are excluded. For instance, “. . . the directive only takes effect when ‘my death is imminent’. Thus many patients would not be permitted to have treatment stopped (by signing the directive) at a time when they are declining and treatment has become burdensome, useless, or both, but when death is still not imminent.”<sup>259</sup>

In effect then the most serious danger of these Bills is that the patient-centered perspective may be given less, rather than more, protection and scope. As one comment on the California Bill put it, “The right to withhold or withdraw useless treatment applies to ‘natural’ as well as ‘artificial’ means, and to situations where the patient has not signed a ‘directive’ and is not competent. . . Physicians welcome AB 3060 because it exculpates them in specified circumstances. But if the signing of this Bill would make them hesitant to follow their religious and moral traditions in circumstances not covered by AB 3060, then patients’ rights will be abrogated and it will in fact become *harder* to die.”<sup>260</sup>

It is sometimes argued that natural death/living will legislation is primarily necessary because otherwise physicians will continue to treat the terminally ill too vigorously, despite patient wishes. Three points can be made against this argument.

First of all it is true that some studies indicate that patients who are seriously or terminally ill do have difficulty communicating their wishes to their physicians.<sup>261</sup> But while this may well be an argument for written living wills, it is not necessarily one for “legislated” living wills.

Secondly, some surveys indicate that the cases in which physicians are likeliest to actively treat against the wishes of patients or patient agents are not those in which death is imminent, but those in which the patient can be maintained for a considerable period of time.<sup>262</sup> But such patients are not even “qualified” to write directives according to most living will legislation. As for the

imminently terminally ill, some surveys suggest most physicians do respect patient wishes about the nature and extent of care.<sup>263</sup>

Thirdly, these surveys do suggest that a majority of physicians, when they do not accede to patient wishes, hesitate because they fear that to accede might constitute malpractice or even make them liable to homicide charges.<sup>264</sup> But this is not necessarily an argument for legislated living wills. It may be a better argument for alternative legislation.<sup>265</sup> For instance it may be more direct and to the point to design relevant legislation to clarify more fully the physician's liability in such cases, (if that is the real problem), than to design legislation which pretends that the problem is protecting patients from over-treatment by physicians, and in the process risks increasing precisely that danger.

However, to argue for legislation which at least in general terms clarifies the physician's liability in these and other cases, is not to argue for a form of "no risk", "no fault" decision making for physicians by providing some form of legal immunity for all cases in which physicians cease treatment for terminally ill incompetent patients. A degree of risk and personal responsibility in such decision making will and should remain, and it would undoubtedly be a form of irresponsibility for physicians to wish to defer or escape making decisions and taking action until and unless they are provided with guaranteed legal immunity, or absolute prior certainty in every case as to their legal liability.

After all, no other profession regularly exposed to decision making in which the death of others is an ever present possible result (soldiers, police, airline pilots, etc.) is granted that kind of immunity. It is worth recalling that, "Because these decisions, dispensing life and by necessary implication dispensing death, press upon our most basic communal identities, I think it proper that society impose an extraordinary burden of care-taking on these physicians. The possibility of criminal liability should force these physicians to give of themselves, to identify both with the family and with the newborn child as if the suffering were the physician's own. . . ." <sup>266</sup>

## PART IV

# CONCLUSIONS: SOME PRIORITIES FOR PUBLIC POLICY AND LAW

### Preamble

(1) On the one hand law is entitled to address itself to the issues dealt with in this paper. There are important individual and societal values to be underlined, rights and duties to be protected, public debate to be invited and formal decision-making and conflict-resolution processes to be used and evolved. All of these, in part at least, are the proper tasks of the legislative forum (Parliament and Provincial Assemblies) and of legal justice (laws and courts). The former to focus public debate and formulate public policy, the latter to dramatize and articulate the ideals of legal justice — impartiality, objectivity, consistency, fairness and equality.

(2) But on the other hand (as noted in the Introduction), the mere presence of endangered values and rights or of immorality does not necessarily mean in every instance that law should be brought more directly and frequently into play. In some instances it may be too blunt, too insensitive to better the situation. More law and legal process may in some instances only further bureaucratize and depersonalize a medical system which, by general consensus, has already gone too far in that direction.

Wherever possible there should be room for both an ethic of rights and an ethic of responsibility in any law reform proposal. The general maxim that law should play a limited, "last resort" role is applicable to our issues. In many instances there may be people,

processes and socializing agencies at more fundamental, more immediate levels better able to encourage responsibility and protect the rights in question. About any particular medically oriented issue there is therefore some onus on legislators and law reformers to establish not only that this or that particular law is better than another, but that law itself belongs here, is likely to do a better job than another and perhaps less intrusive means or at least likely to play a useful supplementary role.

(3) When it comes to the formulation or re-formulation of particular public policies, laws or law reforms in this area, an essential and primary consideration is the determination of just where the real problem is, which particular issue should be regulated or legislated to best cope with a perceived problem and endangered rights, and which issues if directly regulated or legislated in might actually finish by only further depriving these or other patients of the very rights one seeks to better protect.

(4) Legislation or any other form of social policy enacted or reformed in any of the areas discussed in this paper, should not seek to provide for physicians a form of "no fault" immunity from prosecution or civil suits. Even if such legislation were feasible, it would not likely promote the high standard of care encouraged by continuing to allow all such medical decision-making to be reviewable by courts, and by continuing to allow physicians (and others involved in these decisions) to be responsible for their decisions and actions. Rather than seeking full legal immunity, physicians should continue to accept the responsibility of sometimes allowing a patient to die by ceasing or not beginning useless or burdensome-to-patient treatment, and at other times accept the responsibility of not neglecting patients who are treatable and able to be cared for, even though their quality of life is minimal. In any clarification of responsibility and liability in these matters, it should be stated or assumed that the sanctity of life principle imposes a greater burden of proof on those who would allow to die than on those who would continue to treat.

(5) In view of the fact that this paper was not intended to be an in-depth analysis and evaluation of existing law, the specifics which follow are not necessarily meant to be proposals for law reform. In some instances at least, the law may already adequately reflect the (moral) concerns expressed in these specifics. That is for others to

determine. They are offered only as a summary and selection of some of the moral considerations dealt with in this paper, those which ought to be central concerns in public policy, law and law reform as regards the protection of both the sanctity of life and the quality of life.

### Specifics\*

(1) Public policy and law should (continue to) affirm and protect the absolute value, equality and "sanctity" of human life, and continue to prohibit (active) euthanasia for any reasons. But at the same time, it should make explicit that what it is affirming and protecting is the absolute value of human *personal* life, of persons.

(2) Public policy and law should acknowledge that sometimes death of the person may and will have to be established by a quality of life criterion, namely that of irreversible brain death (either of the whole brain or of the cerebral centres). And this even though human biological life in the form of circulatory and respiratory function continue, either spontaneously (in the case of cerebral death only) or artificially (in the case of whole brain death). It should be explicitly affirmed that physicians have no legal liability for not initiating or for ceasing "life" saving or "life" supporting treatment in such cases of biological human life alone, assuming of course that all the necessary tests have been carefully made.

(3) Public policy and law should acknowledge that even in the presence of human personal life there can exist good quality of life reasons for not initiating or for ceasing medical treatment. Applied to both competent and incompetent patients the determinative criterion is the *patient's perspective*, the patient's benefit. In the case of competent patients, they should be free to interpret and determine what is to their benefit by themselves, refusing treatment on any grounds they wish. Decisions by others for incompetent or incoherent patients should be made according to the "reasonable person" test, determining both whether the treatment is *useful* and whether it would occasion *serious patient-centered objections* or burdens. Physicians who cease or do not initiate life saving or life supporting treatment either because the treatment is not useful, or

---

\* For more detailed conclusions see the concluding sections of chapters 1-6.

would occasion a serious patient-centered objection, or both, should not incur legal liability.

(4) But if quality of life criteria are to be given any normative value in public policy and law for purposes of determining whether a particular medical treatment is (or was) useful as well as not excessively burdensome to the patient, then two serious dangers must be protected against. It is by no means certain that adequate protection can in fact be included in such laws and public policies.

The first danger would be to leave the term "quality of life" too vague and general, simply allowing "reasonable medical judgment" to determine the meaning and normative weight to be given to quality of life factors in given cases. Unless relevant public policy and law can articulate and defend some *substantive* quality of life criteria, the mere recognition of such criteria in general without any further specificity would probably be at best unhelpful, and at worst dangerously vague.

In other though related matters laws have usually been formulated in somewhat general terms, leaving it to the particular profession to determine and add the specifics to general (legal) standards such as "reasonable care and skill". But in the matter of quality of life standards in the medical context, this (traditional) manner of formulating relevant law would probably be inadequate. "Quality of life" as a norm for life and death medical decision-making is too elastic a term, and too much in need of public review and control to be "legalized" without carefully drawn definitions and parameters. Whether laws *can* in fact be moved in this direction in this matter is for others to decide.

The second danger in such a recognition would be to articulate quality of life criteria which have not been purged of any connotation of social utility, relative worth or merely subjective considerations. Such criteria would expose incompetent and non-competent patients to more risks than benefits. Therefore the criteria should not only be substantive, but as objective and patient-oriented as possible.

The two criteria suggested in this paper merit consideration. The first considers the patient's capacity to experience and relate. The second considers the intensity and the susceptibility to control of the patient's pain and suffering. If, even with treatment and loving care, a reliable diagnosis and prognosis indicates that there is not now and

apparently never will be even a minimal potential capacity to experience and relate, or that the level of pain and suffering will be prolonged, excruciating and intractable, then and only then would a decision to cease or not initiate life supporting or life saving treatment for an incompetent or non-competent patient be beneficial and acceptable.

(5) It should be clear and explicit in public policy and law that all patients have the right to refuse treatment by withholding consent, even if death will inevitably result. This applies to both competent and incompetent patients. The competent should make such decisions for themselves, and for the incompetent or incoherent, a previously chosen agent, family member, or court appointed guardian (and in that order of authority) would exercise that right for them. The mere refusal of a "dying-prolonging" treatment by a competent patient should not be used as grounds for declaring a person incompetent.

(6) In the case of presently incompetent or incoherent (but formerly competent and coherent) patients, it should be clearly recognized in public policy and law that their wishes regarding initiation, continuation or cessation of treatment which were clearly and knowledgeably expressed when competent and coherent, are to be now respected.

(7) Since, as this paper has argued, medical (curative) *treatment* may be stopped under certain circumstances, though *care* or comfort continue to be morally obligatory, the law should recognize and define as clearly as possible the distinction between what I have called "(curative) treatment" and "(palliative) care". Clarity in this regard would make it possible to establish with (more) accuracy in what sorts of circumstances it is the physician's duty to treat as well as care, and when no such duty to treat exists, but only one of caring.

(8) Knowledgeable and informed medical decisions by patients or proxies to initiate, continue or cease treatment on the basis of quality of life considerations are impossible without full information and understanding as to the diagnosis, prognosis, risks and benefits involved. Such information and understanding is obviously all the more crucial in decisions involving life supporting or life saving



treatment. Therefore any relevant public policies and legislation concerning medical decision-making of this nature should be clear and unambiguous as to the patient's right not only to withhold consent, but also to be fully and clearly informed, and the physician's duty to so inform. When necessary of course, both the patient's right to be fully informed and the patient's right to withhold consent, will be exercised by a proxy (or proxies) for that patient.

## Endnotes

1. For a helpful discussion along these lines see Steve Wexler, "The Interaction of Law and Morals", *The Canadian Bar Review*, 54, 2, June '76, pp. 351-359.
2. One of the best recent treatments of the mutual interaction of law and religion from both historical and contemporary perspectives, is that of the Harvard Law Professor, Harold J. Berman, in *The Interaction of Law and Religion*, Abingdon Press, N.Y. 1974. See also Basil Mitchell, *Law Morality and Religion in a Secular Society*, Oxford U. Press, London, 1970.
3. It would not be accurate to suggest that there is *always* a gap between legal theory and practice in these cases. For instance, the law tends to be very skeptical both in theory and practice about medicine's ability to predict imminent death, or the likely level and extent of recovery if treatment is continued or initiated. Courts tend to put a very high value on even slight chances of survival. A number of recent court cases in the U.S. suggest that the present legal duty of intensive care unit staff for instance is to continue their efforts on behalf of the patient as long as there is any measurable chance of survival, even as little as one or two percent. See George T. Annas, "Decision Making and the Critically Ill Patient: Some legal Aspects of a Patient Classification Scheme", *Linacre Quarterly*, 42, 2, May '75, 116-122.
4. While no case clearly involving euthanasia has yet been decided by a Canadian court, there have been cases in the U.S. and Britain, both of which have much the same legal principles and laws as Canada. Presumably Canadian decisions would be similar in "euthanasia" type cases. Regarding the defence of insanity, see Sanders, Joseph, "Euthanasia—None Dare Call it Murder", *Journal of Criminal Law Criminology and Police Science* No. 3, 1969, 351-359.
5. Becker, Ernest, *The Denial of Death*, Macmillan, N.Y., 1973.
6. Choron, Jacques, *Death and Western Thought*, Collier, N.Y., 1963.
7. Ariès, Philippe, *Western Attitudes Toward Death, from the Middle Ages to the Present*, Johns Hopkins U. Press, Baltimore, 1974.

8. Illich, Ivan, *Medical Nemesis*, McClelland and Stewart, Toronto, 1975.
9. Callahan, Daniel, "The Sanctity of Life", in Donald R. Cutler (ed.), *Updating Life and Death*, Beacon Press, Boston, 1968, p. 185. For much of what follows on the sanctity of life I am indebted to this analysis by Callahan.
10. Kohl, Marvin, *The Morality of Killing*, Humanities Press, Atlantic Highlands, N.J., 1974, p. 3.
11. Williams, Granville, *The Sanctity of Life and the Criminal Law*, Faber and Faber Ltd., London, 1958.
12. See Harold J. Berman, *The Interaction of Law and Religion*, op. cit., note 2, pp. 49-76. See also, Julius Stone, *Human Law and Human Justice*, Stanford U. Press, Stanford, California, 1968, especially pp. 9-35.
13. Barth, Karl, *Church Dogmatics*, Vol. 3, Part 4, T. & T. Clark, Edinburgh, 1961, p. 339.
14. Ramsey, Paul, "The Morality of Abortion", in John Rachels (ed.), *Moral Problems: A Collection of Philosophical Essays*, Harper & Row, N.Y. 1971, pp. 11-12.
15. St. John-Stevas, Norman, *The Right to Life*, Holt, Rinehart and Winston, New York, 1964, p. 12.
16. Ramsey, Paul, op. cit., (note 14) p. 13.
17. Callahan, Daniel, op. cit., (note 9) p. 190.
18. In the final analysis the latter part of this statement is not very helpful as it stands. The expressions, "human nature" and "radical change" are vague and general without further specification. What exactly is "human nature"? What specific changes would be "radical"? Later in the paper (especially in the "person as a normative concept" section) I will attempt to deal in some detail with the first question, at least as it relates to issues of death and dying. As for the second question, it is of course largely dependent on the first. One can only begin to know what changes and what acts (medical or experimental or behaviour modifying) come under the heading of "radical" once one has opted for a particular view of the distinctively and normatively human. But since even "radical" change admits of levels and degrees, debate will (and should) continue, even among those who agree generally on the normatively human characteristics, as to whether the change resulting from a particular medical act is radical or minor.
19. This latter point is made emphatically by St. John-Stevas, who writes, "This respect for human life has become part of the moral consensus of Western society. It has got there, as Sir Patrick Devlin says of the permanent marriage contract, 'because it is Christian, but it remains there because it is built into the house in which we live and it could not be

removed without bringing it down' . . . Once the principle of the sanctity of life is abandoned, there can be no criterion of the right to life, save that of personal taste." St. John-Stevan, op. cit., (note 15) pp. 12, 17.

20. Gustafson, James M., "The Contributions of Theology to Medical Ethics", *Perspectives in Biology and Medicine*, Winter '76, p. 270.
21. Shils, Edward, "The Sanctity of Life", in Daniel H. Labby (ed.) *Life or Death: Ethics and Options*, U. of Wash. Press, Seattle, 1968, pp. 2-38.
22. Ibid, p. 9.  
  
Shils in fact goes further and argues that "The transcendent sacred is a construction which the human mind itself has created to account for and to place in a necessary order the primordial experience and vicissitudes of the actual embodiment of vitality to which it attributes sacredness" (p.13). "If man did not prize his own vitality, the sacred and its vast symbolic elaboration into cosmogonies and theologies would not exist" (p. 14).
23. Ibid. pp. 12-13.
24. Medawar, P. D., "Genetic Options: An Examination of Current Fallacies", in Daniel H. Labby (ed.), *Life and Death: Ethics and Options*, U. of Wash. Press, Seattle, 1968, p. 78.
25. Barth, K., op. cit., (note 13) p. 339.
26. Shils, E., op. cit., (note 21) p. 15.
27. Clouser, K. Danner, "The Sanctity of Life: An Analysis of a Concept", *Annals of Internal Medicine* 78: 119-125, 1973, pp. 120, 121.
28. Shils, E., op. cit., p. 19.
29. Kluge, Eike-Henner W., *The Practice of Death*, New Haven and London, Yale University Press, 1975, p. 142.
30. Pendengast, Richard J., Letter, *Annals of Internal Medicine* 78, 6, June, 1973, p. 979.
31. Winget, C., Kapp, Frederic T., Yeaworth, Rosalee C., "Attitudes Towards Euthanasia", *Journal of Medical Ethics*, 3, 1977, p. 20.
32. Tendler, Dr. Moshe, as cited by Howard Brody in *Ethical Discussions in Medicine*, Little, Brown and Co., Boston, 1976, p. 66.

A similar Jewish view is expressed by Byron Sherwin, "According to Jewish law, life is to be preserved, even at great cost. Each moment of human life is considered intrinsically sacred. Preserving life supersedes living the 'good life'. The sacredness of life and the uniqueness of the individual require that every possible action be taken to preserve life." "Jewish Views of Euthanasia", in Marvin Kohl (ed.), *Beneficent Euthanasia*, Prometheus Books, N.Y., 1975, p. 7.

33. Rostand, Jean, *Humanly Possible: A Biologist's Notes on the Future of Mankind*. Saturday Review Press, N.Y. 1973.
34. DeMarco, Donald, *Catholic Register*, Jan. 23, 1978.
35. Carter, Bishop E., as cited by Wilfred Murphy in the *Elmira Ontario Independent*, Nov. 30, 1977.
36. Rostand, Jean, op. cit. (note 33).
37. I say "may" because as a historical fact there is some uncertainty as to what the original intentions of the Nazi program were. Some maintain that racism—purification of the Aryan stock—was in fact the original intention. It is probably not a coincidence that those of this view tend to be in favour of (direct) euthanasia and argue from this (against the wedge argument) that the Nazi experience does not provide a good (wedge) argument against euthanasia, as that program was compromised from the beginning. Indiscriminate euthanasia (they argue) is therefore likely only in a Nazi like society. See for instance Marvin Kohl, "Voluntary Beneficent Euthanasia", in Marvin Kohl (ed.) *Beneficent Euthanasia*, Prometheus Books, Buffalo, N.Y. 1975, p. 137. But for another view see Leo, Alexander, "Medical Science under Dictatorship", *New England Journal of Medicine*, 241 (1949) pp. 39-47, and Davidowicz, Lucy C., *The War Against the Jews, 1933-1945*, Holt, Rinehart and Winston, N.Y. 1975, pp. 131-34. There is some evidence suggesting that a euthanasia policy for largely utilitarian and racist reasons might in fact be acceptable even in our contemporary society. See Mansson, Helge Hilding. "Justifying the Final Solution", *Omega*, 3, (1972) pp. 79-87.
38. Bettelheim, Bruno, *The Informed Heart*, London, 1961.
39. Kluge, Eike-Henner W., op. cit., (note 29) p. 137.
40. Gustafson, James N., "Basic Ethical Issues in the Biomedical Fields", *Soundings*, 53, Summer 1970, p. 164.
41. Kaplan, Abraham, "Social Ethics and the Sanctity of Life: A Summary", in Daniel H. Labby (ed.), *Life or Death: Ethics and Options*, U. of Wash. Press, Seattle, 1968, pp. 154-155.
42. Editorial, *The Globe and Mail* (Toronto), April 13, 1978, p. 6.
43. Fletcher, Joseph, "The Right to Live and the Right to Die", *The Humanist* 34, 4, July-August, 1974, p. 12.
44. *Ibid.*, p. 13.
45. *Ibid.*, p. 13.
46. Clouser, K. Danner, op. cit., (note 27) p. 121.
47. *Ibid.*, p. 122.
48. *Ibid.*, p. 122-123.

49. Kohl, Martin, *The Morality of Killing*, op. cit., (note 10) p. 30.
50. Ibid., p. 95.
51. The leading theologians of these "schools" are both Protestant and Catholic, and include: Dietrich Bonhoeffer, Karl Rahner, Johannes Metz, Harvey Cox, Rudolf Bultmann, W. Pannenberg, Gustave Thils, Friedrich Gogarten, Teilhard de Chardin and many others.
52. Bonhoeffer, Dietrich, *Letters and Papers from Prison*, Macmillan, N.Y., 1962, p. 196.
53. Pastoral Constitution, *Gaudium et Spes*, on the Church in the Modern World, in *The Documents of Vatican II*, Walter M. Abbot (ed.), London, 1966, no. 36.
54. Metz, Johannes, *Theology of the World*, The Seabury Press, N.Y., 1973, p. 57.
55. Ibid., p. 59.
56. Ibid., p. 57.
57. Ibid., p. 58.
58. Ibid., p. 64.
59. Ibid., p. 67.
60. Ibid., p. 74.
61. Rahner, Karl, "Experiment Man", in *Theology Digest*, Sesquicentennial Issue, Feb. 1968, p. 61.
62. Guttmacher, Alan F., "The United States Medical Profession and Family Planning", in Bernard Berelson (ed.), *Family Planning and Population Programs*, U. of Chicago Press, Chicago, 1966, p. 458, as cited by D. Callahan, "The Sanctity of Life", op. cit., p. 216.
63. Gustafson, James, "Basic Ethical Issues in the Biomedical Fields", op. cit., (note 40) p. 164.
64. Aiken, Henry David, *Reason and Conduct*, Alfred A. Knopf, N.Y. 1962. See especially ch. 4, "Levels of Moral Discourse". I am equally indebted to Daniel Callahan for suggesting the application of Aiken's view to the sanctity of life principle in particular (see his, "The Sanctity of Life", op. cit., note 9, pp. 196-202).
65. Ibid., p. 71.
66. Ibid., p. 75.
67. Gustafson, James, "Basic Ethical Issues in the Biomedical Fields", op. cit., (note 40) p. 152.

68. Aiken, Henry David, *op. cit.*, (note 64) p. 76.
69. *Ibid.*, p. 77. To "go beyond ethics altogether" would take us to what Aiken calls the "post-ethical" level—see Aiken p. 83 ff. It would take us too far afield to include a discussion here, especially since that would get us into a major issue in ethics, namely, "Why should one be moral?"
70. *Ibid.*, p. 80.
71. *Ibid.*, p. 82.
72. *Ibid.*, p. 82.
73. Callahan, D., "The Sanctity of Life", *op. cit.*, note 9, p. 198.
74. For one of the more detailed and perceptive treatments of moral rules, see Gert, Bernard, *The Moral Rules*, Harper & Row, N.Y., 1970.
75. This list of rule systems and much of what follows is from D. Callahan, "The Sanctity of Life", *op. cit.*, (note 9) p. 201 ff.
76. *Ibid.*, p. 208.
77. This point has been well made by Abraham Edel. "The domain of ignorance is and will be indefinitely vast. But from a practical point of view, it can no longer be used as an *a priori* veto on attempts at knowledge and control. In more stable days, it could be said that no experimental ventures should be made in human life which involved a plunge into the unknown, because disasters might result. Now the same argument can be urged against *not* making experimental ventures; for the consequences of continuing in the old ways in a rapidly changing world may be quite as unknowable and quite as disastrous. This argument does not justify recklessness in experiment; we are learning how reckless we have been. But it underlines the recklessness of conservatism too. In short the emphasis falls on responsible attempts at control." "Scientists, Partisans and Social Control", *Transaction*, Jan. 1972, p. 34.
78. Editorial, *California Medicine*, Sept. 1970, pp. 67-68.
79. Weber, Leonard J., *Who Shall Live?* Paulist Press, N.Y., 1976, pp. 41-42.
80. *The Quality of Life Concept*, U.S. Environment Protection Agency, Washington, D.C., 1973, p. iii.
81. Baier, Kurt, "Towards a Definition of Quality of Life", in Peter C. List and Ronald O. Clarke (editors), *Environmental Spectrum*, D. van Nostrand Co., N.Y., 1974, p. 67.
82. See for instance, U.S. Environmental Protection Agency, *Quality of Life Indicators*, 1972. Also, Dillman, Don A., and Tremblay, Kenneth R., "The Quality of Life in Rural America", *The Annals of the American Academy of Political and Social Science*. 429, Jan. '77, 115-129.

83. See for instance, Office of Management and Budget (U.S.), *Social Indicators*, Washington, 1973, p. xiii, also, *Perspective Canada*, Ottawa, 1974, p. xxii.
84. McCall, Sorrs, "Human Needs and the Quality of Life", in John King-Farlow and William R. Shea (editors), *Values and the Quality of Life*, Canadian Contemporary Philosophy Series, Science History Publications, N.Y., 1976, p. 14.
85. *Ibid.*, p. 15.
86. *Ibid.*, p. 18.
87. Maslow, Abraham, *Motivation and Personality*, N.Y., 1954. pp. 35-47, as cited by McCall, *op. cit.*, p. 19.
88. This is a suggestion convincingly argued by Storrs McCall, *op. cit.*, note 84, pp. 20-21.
89. Baier, Kurt. "The Sanctity of Life", *Journal of Social Philosophy* 5, (2), April '74, p. 5.
90. For probably the best treatment of the obligation and significance of "Care", see Paul Ramsey, "On (Only) Caring for the Dying", ch. 3 of his *The Patient as Person*, Yale University Press, New Haven, 1970, pp. 113-164.
91. Kautzky, R. "Der Arzt", *Arzt und Christ* 15 (1969), 138, (as cited by R. McCormick, "The Quality of Life, The Sanctity of Life", *Hastings Center Report*, 8, 1, Feb. '78, p. 34).
92. One can think of no compelling moral or medical reason why, once death has been declared, such "unburied corpses" cannot continue to be maintained biologically alive for any length of time as "vital organ banks" or "tissue banks". As one moralist puts it, "it seems to me that one should not speak in such cases of having maintained 'life'. For what is really maintained is merely certain limited biological functions. To put it more pointedly, there has been a preservation of the vitality of specific organs of an unburied corpse . . . the organism as a whole has ceased to be . . ." Thielicke, Helmuth, in Kenneth Vaux (ed.) *Who Shall Live? Medicine, Technology, Ethics*, Fortress Press, Philadelphia, 1970, p. 176.
93. Capron, A. M. and Kass, L. R., "A Statutory Definition of the Standards for Determining Human Death: an Appraisal and a Proposal", *U. of Penn. Law Review*, 121, Nov. 1972, p. 111.
94. The major such test would be the presence of a flat EEG (Electroencephalogram). Because some brain activity can apparently still remain even if the EEG indicates no electrical activity, it can be only of confirmatory value for the determination of *whole brain* death. But because it measures mainly neocortical or higher brain activity, it can be the central and major test for *cerebral* death. Its reliability for that purpose has been



strongly supported by medical evidence. See D. Silverman *et al.*, "Irreversible Coma Associated with Electroencephalographic Silence." *Neurology*, 20, 1970, 525-533. For a fuller discussion of brain death and cerebral death, see: Veatch, Robert, "The Whole-Brain-Oriented Concept of Death: An Outmoded Philosophical Formulation", *Journal of Thanatology* 3, 13 (1975) and his, *Death, Dying and the Biological Revolution*, Yale U. Press, New Haven, 1976, pp. 21-76; Brierley, J.B. *et al.*, "Neocortical Death after Cardiac Arrest", *Lancet*, Sept. 11, 1971 pp. 560-565; Capron, Alexander Morgan and Kass, Leon R., "A Statutory Definition of the Standards for Determining Human Death: An Appraisal and a Proposal", *U. of Pennsylvania Law Review*, 121, Nov. 1972, p. 97. For further proof (if any is required) that this paper's discussion of death and brain death has merely skimmed the surface of a very complex, long debated and fascinating subject, see the collection of readings edited and introduced by Antony Flew in his, *Body, Mind and Death*, Macmillan, N.Y., 1964. The readings, ". . . have been selected in the light of the editorial conviction that the fundamental issues outstanding are primarily philosophical rather than scientific. Yet, equally certainly, they are issues that can be resolved satisfactorily only by a philosophy receptive to a scientific outlook, and informed by scientific knowledge." (p. 2). For a scientific (but very readable) history of the human brain, see Carl Sagan's, *The Dragons of Eden*, Ballantine Books, N.Y., 1977.

95. Ariès, Philippe, *Western Attitudes Toward Death, from the Middle Ages to the Present*, Johns Hopkins U. Press, Baltimore, 1974, p. 88.
96. Diggory, J. C., and Rothman, D. Z. "Values Destroyed by Death", *Journal of Abnormal and Social Psychology*, 63, 1961, 205-210.
97. Gellman, Derek, M.D. *Dimensions in Health Services* 52, Nov. '75, p. 23.

One of the central points argued earlier in this paper in dealing with the sanctity of life is worth recalling here, and has been well stated by Richard McCormick: "In the past the Judeo-Christian tradition has attempted to walk a balanced middle path between medical vitalism (that preserves life at any cost) and medical pessimism (that kills when life seems frustrating, burdensome, 'useless'). Both of these extremes root in an identical idolatry of life—an attitude that, at least by inference, views death as an unmitigated, absolute evil, and life as the absolute good. The middle course that has structured Judeo-Christian attitudes is that life is indeed a basic and precious good, but a good to be preserved precisely as the condition of other values. It is these other values and possibilities that found the duty to preserve physical life and also dictate the limits of this duty. In other words, life is a relative good, and the duty to preserve it a limited one." ("To Save or Let Die", *Journal of the American Medical Association*, 229, 2, July 8, 1974, p. 174).

98. Weber, Leonard J., *op. cit.*, (note 79) p. 83.
99. McCormick, Richard A., "The Quality of Life, The Sanctity of Life", *Hastings Center Report* 8(1), 1978, p. 35.

100. Fletcher, Joseph, "The Right to Live and the Right to Die", *The Humanist*, 34(4), Aug. '74, p. 13.
101. Morrison, Robert S., "The Dignity of the Inevitable and Necessary", in Peter Steinfelds and Robert Veatch (editors) *Death Inside Out*, Harper and Row, 1974, p. 98.
102. Englehardt, H. Tristram, "The Counsels of Finitude", in *Death Inside Out*, op. cit. (note 101), p. 124.
103. Fletcher, Joseph, op. cit., (note 100) p. 13.
104. Kübler-Ross, Elisabeth, *Death, The Final Stage of Growth*, Prentice Hall Inc., Englewood Cliff, N.J., 1975, p. 6.
105. Zilboorg, G., "Fear of Death", *Psychoanalytic Quarterly*, 12, 1943, p. 467.
106. Ramsey, Paul, "The Indignity of Death with Dignity", in *Death Inside Out*, op. cit. (note 101), p. 82.
107. Kluge, Eike-Henner W., *The Practice of Death*, Yale University Press, New Haven, 1975, p. 155.
108. Barth, Karl, *Church Dogmatics*, Vol. 3, Part 4, T. Clark, Edinburgh, 1961, p. 246.
109. For a recent and excellent application of this and other ethical principles (beneficence and justice), see, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report. Ethical Principles and Guidelines for the Protection of Human Subjects of Research*, DHEW Publication No. (OS) 78-0012, Wash. D.C., 1978.
110. Callahan, Daniel, *The Tyranny of Survival and other Pathologies of Civilized Life*, Macmillan, 1973, p. 164.
111. Ramsey, Paul, *The Patient as Person*, op. cit. (note 90).
112. Hauerwas, Stanley, "Must a Patient be a 'Person' to be a Patient?", *Connecticut Medicine*, 39 (12), 1975, p. 185.
113. *Ibid.*, p. 816.
114. Bok, Sissela, "Who Shall Count as a Human Being? A Treacherous Question in the Abortion Discussion", in Robert L. Perkins (ed.), *Abortion, Pro and Con*, Schenkman, Cambridge, Mass., 1974, p. 96.
115. *Ibid.*, p. 97.
116. *Ibid.*, p. 97.
117. For more on this point and on the subject of witches, see the insightful historical study by H. Trevor-Roper, *The European Witch-Craze of the*

*16th and 17th Centuries*, Penguin Books, 1967. He notes, "The concepts of a pact with the Devil, of night-riding to the sabbat, of *incubi* and *succubi*, may derive from the pagan folk-lore of the Germanic peoples. But the weaving together of these various elements into a systematic demonology which could supply a social stereotype for persecution was exclusively the work, not of Christianity, but of the Catholic Church . . . Like the Jew, the witch became the stereotype of the incurable nonconformist; and in the declining Middle Ages the two were joined as scapegoats for the ills of society . . . In the mid-sixteenth century, the craze was revived and extended, and the years from 1560 to 1630 saw the worst episodes in its long history. It seems incontestable that the cause of this revival was the intellectual regression of Reformation and Counter-Reformation, and the renewed evangelism of the rival Churches." (pp. 114-116) The reader may feel that I have belaboured at too great length the subject of witches and "personhood". However it seemed a useful exercise in order to demonstrate that it may be more facile than historically accurate to assume that denial of "personhood" has always been the cause or focal point of the denial of rights to certain peoples and groups.

118. Hostler, John, "The Right to Life", *Journal of Medical Ethics*, 3, 1977, p. 143.
119. Maclean, Elizabeth A. "Dignity", *Journal of Medical Ethics*, 3, 1977 p. 41.
120. *Ibid.*, p. 41.
121. Shaw, Anthony, "Defining the Quality of Life", *Hastings Center Report* 7 (5), Oct. 1977, p. 11.
122. *Ibid.*, p. 11.
123. *Ibid.*, p. 11.

For contexts wider than the one under consideration here one would even agree (enthusiastically) that not only does a subject's quality of life considered fully include such (environmental) factors, but so does his personhood. A fuller "definition" of personhood than the minimal one needed here would go well beyond the *capacity* to relate, and would include *actual* relationships somewhere near the center of what a person is and what makes a person. Therefore we would generally agree that, ". . . a person is not identical with merely the qualities inhering in a particular mind-body having certain spatiotemporal boundaries. Because we identify specific persons by pointing to their bodies or by referring to their performances, the *logic* of personal identity requires such boundaries; but this does not entail that the *nature* of personhood be similarly restricted. Personhood inheres in a complex network of relationships, not only in the aforementioned qualities. . . . for there is a rationally interpersonal life with numerous relationships uniting them in fealty to others and unifying their lives by loyalty to ideals . . . they prosecute ideals, they share achievement and failure, they love and are loved . . . were there no such relationships, human beings would be no more than highly complex organisms." Robert Hoffman, "Death and

Dignity", in Marvin Kohl (ed.), *Beneficent Euthanasia*, Prometheus Books, N.Y., 1975, p. 75.

An excellent philosophical analysis of similar themes is found in Brian Wicker's *Culture and Theology* (Sheed and Ward, London, 1966). Particularly relevant to notions of personhood are pages 48-101, in which he discusses Merleau-Ponty, Wittgenstein and Marx. He demonstrates that, "For Merleau-Ponty, perceptual experience presents us with a world which is not standing over against us, but is first of all that in which we inhere, and which gives us our own identity as individuals. From this position it is possible to go on to show (with Wittgenstein) that this world is more than something given in perception: it is a world structured, to its very roots, by our own capacity for, and use of, language. We live in a linguistic world: and it is this world which gives us our own humanity. Finally, Marx adds to this insight the understanding that the linguistic world becomes ours only because we are trying all the time to transform it, to humanize it, in the process of ensuring our survival in it—that is, by the economic process." (p. 15).

One crucial implication of all this for our concerns is that it would be simplistic indeed for either medical decision-making or health policy choices (and any translation of same into law) to always assume a polarity between the individual and society, to assume that those decisions and choices must always favor one at the expense of the other. As Daniel Callahan writes, "The great threat to the possibility of a social ethic for a technological society is less the absence of all values than the triumph of one value over all others. Both individualism and survival [of the community] are struggling to achieve that position, with a striking degree of success. Nothing is more important than to deny both the triumph they seek." *The Tyranny of Survival and Other Pathologies of Civilized Life*. Macmillan, N.Y., 1973, p. 135.

124. One cannot fail to be enormously impressed by the heroic and compassionate care extended to seriously defective newborns and infants by parents and other members of families, as well as by the staff of institutions. And, undoubtedly such experiences provide families and institutional staffs with the opportunity for learning and extending compassion, love and fidelity with a degree of intensity and responsibility provided by few other experiences in life.

One physician, after listing the many possible serious defects which newborns can have, writes, "I treated a boy who had half of these things plus a few others. He has had more than twenty-five operations. I see him and his family in the community about once a week. They are a great family and consider the boy and his problems to be the best experience life has offered them. The boy is a delight. He has strengthened the family and has taught them compassion and understanding." (C. Everett Koop, M.D., *The Right to Live, The Right to Die*, Tyndale House Publishers, Inc., Wheaton, Illinois, p. 23).

Another physician expressed much the same thought, but this time applied to the staff of institutions. "The institution was immaculate. Someone in the institution was capable of relating closely to every child,

and at every bedside as we made rounds there would be a staff member who could tell us the child's history . . . Severe hydrocephalics and markedly obtunded, neurologically damaged children were called by name and regarded as individuals. Their disease and related irascibility was understood, explained away and assuaged by acts of comfort." (Eugene F. Diamond, M.D., "Quality vs. Sanctity of Life in the Nursery", *America*, 135, Dec. 4, 1976, p. 397).

Yet one cannot avoid two nagging suspicions. One is that in *some* (possibly a very small minority) of these cases, if decisions had been made soon after birth or later not to treat, due to a reliable diagnosis of severe defects and a reliable prognosis of continued and largely intractable pain and suffering (due for instance to continuing and drastic surgical interventions), they may well have been decisions for the benefit of those children. The second and related suspicion is that *sometimes* such decisions are not made at least partially because we, the healthy, derive meaning, purpose, compassion and satisfaction from experiences which can have no such positive features for those defective infants and children (as well as adults) who provide us with these opportunities.

125. Hellegers, André F., "Relating is the Criteria for Life", *Ob. Gyn. News*, Oct. 15, 1974, p. 48.
126. Fried, Charles "Terminating Life Support: Out of the Closet", *New England Journal of Medicine*, Aug. 12, 1976, p. 390.

Eugene Diamond M.D., notes the difference in perspective, and therefore in decisions made between those on the scene when the defective child is born (especially those in intensive care units), and those with responsibility for long term and follow up care. The former (he writes), ". . . are inclined to have a low frustration tolerance and to doubt the validity of large investments of professional time and energy to realize small returns of stable or slightly altered function." But the latter group (he writes) are prepared to settle for those smaller returns. (Eugene Diamond, M.D. "Quality vs. Sanctity of Life in the Nursery", *America*, 135, Dec. 4, 1976, p. 397).

127. Callahan, Daniel, *The Tyranny of Survival and other Pathologies of Civilized Life*, op. cit., (note 110) p. 234.
128. *Ibid.*, p. 288.

On the other hand it is not difficult to think of some hypothetical eventualities in which "burden on others" by allowing a defective child to be born could become so great that it would be morally justified to force its mother to abort it. One such hypothetical example would be that of a foetus discovered by tests to have a severe and contagious infection, which disease would release a deadly and uncontrollable plague into the world if the child were allowed to be born.

Less hypothetical and more urgent are questions and cases concerning the burden, not to "society" but to the severely defective potential child if allowed to be born. One factor which raises this moral question with some urgency are the suits for "wrongful life" initiated in

recent years in a number of countries, on the grounds that life itself in some circumstances constitutes an injury to the living person. Though to my knowledge these suits have so far failed, they have in their successful initial stages raised some serious moral as well as legal questions some of which have implications for our issue here. The basic moral question is of course whether it may be an injustice to a potential child known to be severely defective, to cause or allow him to be born. In these torts it has been argued that when great and intractable suffering or harm can be predicted before birth for that child once born, life itself can be considered not a gift but an injury, and there well may be a *duty* not to give that person existence. In my view it is an argument not without some merit.

While society should not be allowed to forbid the procreation and birth of genetically "imperfect" bodies and minds, it would however seem equally legitimate and quite consistent to argue that couples may sometimes have a "genetic" responsibility, especially to the potential children, to not procreate. This is surely the case when the couple has been provided with genetic information about themselves indicating the strong likelihood that their offspring will be seriously defective because of genetic defects in one or both parents. The sort of "genetic roulette" involved in procreating regardless and hoping for the best, would seem to be almost as distasteful as state eugenic programs which forbid imperfections.

I say "almost" because the latter seems the more potentially dangerous of the two approaches, which in turn leads one to resist any temptation to transform a parental *responsibility* (to weigh the information and sometimes freely decide not to procreate) into a strict duty or law (absolutely forbidding procreation or insisting upon abortion).

129. Bok, Sissela, "Who Shall Count as a Human Being?" *op. cit.*, (note 114) p. 94.

See also André E. Hellegers M.D., "The Beginnings of Personhood: Medical Considerations", *Perkins Journal*, 27,1, 1973. He writes, "Terms like 'personhood' . . . have no meaning in biology. What evidence science can bring to the debate must be restricted to that in which it has competence. This competence is restricted to describing biological facts." (p. 11)". . . I do not consider the abortion debate a medical debate at all . . . In the abortion debate the physician can only state his own perceptions on value judgements about undoubted biological human life . . . one does well to realize that those physicians who decide to perform the abortion do so as a reflection of their personal value perception of unborn human life, rather than on biological or medical fact." (pp. 14-15)

130. See *Roe v. Wade*, 93 S. Ct. 705 (1973) p. 730. *Morganthaler v. The Queen*, (1975) 53 D.L.R. (3d) p. 203.
131. See Kluge, E. H-W., "The Right to Life of Potential Persons", *Dalhousie Law Journal*, Jan. 1977, pp. 837-848.

- 132 See for instance, *Montreal Tramways Co. v. Léveillé* (1933) 4 D.L.R. 337 (for the approach of civil law); *Smith v. Fox* (1923) 3 D.L.R. 785 (Ont. S.C.); *Duval v. Seguin*, 26 D.L.R. 3rd 418 (Ont. S.C. 1972); California Civil Code, 3. 29. This latter states, "A child conceived but not yet born is deemed an existing person so far as may be necessary for its interests in the event of subsequent birth."

See also *In re Holthausen* 26 N.Y.S. 2d 140, at p. 143 (Sur. Ct. 1941), in which a New York court stated, "It has been the uniform and unvarying decision of all common law courts in respect of estate matters for at least the past two hundred years that a child en ventre sa mere is 'born' and 'alive' for all purposes for his benefit."

133. Without resorting to "definitions" of person, law does of course consider the question, "Is this a person with rights and duties in law", a central and decisive one. One seemingly representative view of the subject is that of Howard J. Taubenfeld ("The Beginning of Personhood: Legal Considerations", *Perkins Journal*, 27,1, 1973, pp. 16-19) who writes that, "... there may be a number of answers within the legal system. The analyst needs to ask the context in which the answer to the question, 'Is this a person?' is sought... And the law most appropriately asks, 'Is this a person for purposes of this set of legal considerations?'. The answer may well be yes for some and no for others, as the society has weighed and balanced conflicting interests..." (p. 17). "For purposes of that statute or document the meaning can be found, but that doesn't necessarily define the term for the law..." (p. 18) "... the answers depend not on mystical, metaphysical, or even fully on medical analysis, but on a balancing of conflicting interests and rights and duties..." (p. 19).

An important Canadian example of the way the context or particular law contributes to a court's decision on the question of personhood, is the Supreme Court's judgment in *Montreal Tramways Co. v. Léveillé* (supra, note 132), an appeal based on the *Quebec Civil Code*. The Company argued that the child (born with a deformity suffered while as yet unborn) was not really a person when injured, but only a part of her mother. But the Court rejected that defence, and Mr. Justice Lamont finding in favour of the plaintiff noted that, "... I am of the opinion that the fiction of the civil law must be held to be of general application. The child will, therefore, be deemed to have been born at the time of the accident to the mother. Being an existing person in the eyes of the law it comes within the meaning of 'another' in art. 1053, and is, therefore entitled through its tutor to maintain the action." (Ibid., p. 346)

It has been maintained that, "In *Montreal Tramways Co. v. Léveillé* ... judicial notice was taken of the fact that in some areas the law has long recognized an unborn infant as a person". (Weiler, Karen M. and Cotton, Kathleen, "The Unborn Child in Canadian Law", *Osgoode Hall Law Journal*, 14, 3, Dec. 1976, p. 653). Whether or not that might be claiming too much for "what the law has long recognized", this particular judgment at least (based in large part on an argument of natural justice) did acknowledge the existence of a foetal person meriting the compensation extending to injured persons.

134. See for instance Kluge, E. H. W., "The Right to Life of Potential Persons", op. cit., (supra, note 131) p. 842. Kluge writes, "... an individual may be counted as a person if and only if he is now thus self-aware or can acquire such an awareness without it being necessary that he undergo a fundamental constitutive change in his physiological make-up in order to have such an awareness."
135. to some extent the argument from potential personhood either begs the question or concedes the point that the foetus is not now a person. If one argues that a foetus has the *potentiality* to become a person, one has conceded that it *isn't now* one. If one maintains that the foetus has the potentiality *of* a person, one begs the disputed question—whether foetuses are persons.
136. Bok, Sissela, op. cit., (note 114) p. 99.
137. See for instance, T. S. Clements, *Science and Man: The Philosophy of Scientific Humanism*, Charles Thomas, Springfield, Ill., 1968 (ch. 4); G. G. Simpson, *Biology and Man*, Hancourt, Brace and World, N.Y., 1969.
138. Fletcher, Joseph, "Indicators of Humanhood: A Tentative Profile of Man" *Hastings Center Report*, 2, 5, Nov. 1972, pp. 1-4; "Four Indicators of Humanhood — The Enquiry Matures," *Hastings Center Report*, 4, 6, Dec. '74, pp. 4-7.
139. Fletcher, Joseph, "Indicators of Humanhood: A Tentative Profile", *Ibid.*, p. 1.
140. Fletcher, Joseph, "The Right to Die", *Atlantic Monthly*, April 1968, p. 64.
141. Engelhardt, H. T., "Medicine and the Concept of Person", a paper read as part of the Matchette Foundation Series, "The Expanding Universe of Modern Medicine", The Kennedy Institute and the Dept. of Philosophy, Georgetown University, Washington D.C., Nov. 19, 1974, p. 16. For much of what follows on the subject of person I am indebted to the analysis of H. T. Engelhardt. The position I propose on this point is substantially similar to his.
142. *Ibid.*, p. 13.
143. Engelhardt, H. T., "The Beginning of Personhood: Philosophical Considerations", *Perkins Journal* 27,1, 1973, p. 21.
144. For instance by Michael Tooley, in "A Defense of Abortion and Infanticide", in Joel Feinberg (ed.), *The Problem of Abortion*, Wadsworth Pub. Co., Belmont, Calif., 1973, pp. 51-91.
145. Weber, Leonard, *Who Shall Die?* op. cit., (note 79) p. 85.
146. Ramsey, Paul, "Euthanasia and Dying Well Enough", *Linacre Quarterly* 44, 1, Feb. '77, p. 44.



147. Pope Pius XII, AAS 49 (1957) 1031-32.
148. As cited in John F. Dedek, *Contemporary Medical Ethics*, Sheed and Ward, N.Y., pp. 201-205.
149. *Ibid.*, p. 206-214.
150. Proceedings, A.M.A. House of Delegates, December, 1973.
151. Code of Ethics, Approved by General Council of C.M.A., June 1975.
152. Healy, Edwin, *Medical Ethics*. Loyola University Press, Chicago, 1956, p. 67.
153. Veatch, Robert, *Death, Dying and the Biological Revolution*, Yale U. Press, New Haven, 1976, especially pp. 105-115. In much of what follows in this section I am indebted to his exposition.
154. *Ibid.*, p. 106.
155. *Ibid.*, p. 107.
156. Kelly, Gerald, *Medico-Moral Problems*. The Catholic Hospital Association, St. Louis, 1958, p. 129.
157. Veatch, Robert, *op. cit.*, (note 153) p. 109. See also Paul Ramsey, *The Patient as Person*. *op. cit.*, (note 90) pp. 136-144.
158. If a presently noncompetent but once competent patient expressed a clear wish while coherent (orally or in writing) as to the conditions under which he wished life saving or supporting treatment begun, continued or stopped, then that wish should be respected as a "reason still valid to himself". In our view no compelling argument can be advanced in favour of cancelling such previously expressed wishes because of one's present altered state. Such an argument would ignore the important distinction to be made between those *never* competent and those *previously* competent.
159. *Hunter v. Brown*, 4 Wash. App. 899, 484 p. 2d 1162 (1972). See also *Berkey v. Anderson*, 1 Cal. App. 3d 799, 805, 82 Cal. 67, 68 (1969).
160. *Globe and Mail* (Toronto), June 20, 1978, p. 3.
161. Veatch, Robert, *op. cit.*, (note 153) p. 111.
162. *Ibid.*, p. 112.
163. See Richard McCormick, "The Quality of Life, the Sanctity of Life", *op. cit.*, (note 99) p. 33.
164. *Ibid.* p. 35, citing from, "In the Matter of Karen Quinlan, an Alleged Incompetent," A-116, March 31, 1976, p. 24.

165. It should be noted by way of preliminary that according to the "irreversible cessation of total cerebral function" standard discussed earlier (see p. 62), Karen may perhaps be dead as a person already, though she is able to breathe spontaneously. But since, as also noted, such a standard may not be generally acceptable (it obviously is not to her parents and physicians), it would be "prudent" to consider Karen as being still alive for the purpose of related policy decisions, such as whether or not to continue life support treatment. This in fact is how she was and is considered by her parents and physicians. But as we have already noted at length, the presence of death, the cessation of personhood, is not the only case in which treatment may be stopped. Another reason is that further treatment could not be useful, would only prolong dying.
166. Ramsey, Paul, "Prolonged Dying: Not Medically Indicated," *Hastings Center Report*, 6,1, Feb., 1976, p. 16.
167. Weber, Leonard, op. cit., (note 79) p. 92.
168. McCormick, Richard T., op. cit., (note 99) p. 35.
169. Or perhaps still more accurately "only caring for the dying", as Paul Ramsey labels it. See his, *The Patient as Person*, pp. 113-164.
170. Veatch, Robert, op. cit., (note 153) p. 77.
171. Ramsey, Paul, "Euthanasia and Dying Well Enough", *Linacre Quarterly*, 44 (1977), p. 35.
172. Louisell, David, "Euthanasia and Biathanasia: On Dying and Killing," *Catholic University Law Review*, 22, Summer 1973, p. 730.
173. See for instance Fletcher's, "The Patient's Right to Die," *Harper's*, October 1960, pp. 141-142; "The Right to Live and the Right to Die: A Protestant View of Euthanasia", *The Humanist* (34) 4, July, August 1974, pp. 12-15; "Euthanasia and Anti-Dysthanasia", chapter 9 of his *Moral Responsibility*, Westminster, Philadelphia, 1967, pp. 141-160.
174. Ramsey, Paul, *The Patient as Person*, op. cit., p. 151, see also his, "Euthanasia and Dying Well Enough", op. cit., p. 38.
175. *On Dying Well: An Anglican Contribution to the Debate on Euthanasia*. Church Information Office, Church House, Dean's Yard, London, England, 1975, p. 48.
176. Saunders, Cicely, "The Moment of Truth: Care of the Dying Person", in Francis G. Scott and Ruth M. Brewer. (editors), *Confrontations of Death*. Oregon Center for Gerontology, Corvallis, Oregon, 1971, p. 119.
177. Louisell, David, op. cit., (note 172) p. 731.
178. Ramsey, Paul, "Euthanasia and Dying Well Enough", op. cit., (note 146) p. 40.
179. *On Dying Well*, op. cit., (note 175) p. 40.

180. Rachels, James, "Active and Passive Euthanasia", *The New England Journal of Medicine* 292 (Jan. 9, 1975) pp. 78-80.
181. *Ibid.*, p. 79.
182. See for instance Tom L. Beauchamp, "A Reply to Rachels on Active and passive Euthanasia", *Social Ethics*, McGraw Hill, 1977, pp. 67-74; James Childress, "To Kill or let Die", unpublished paper; Robert Veatch, *Death, Dying and the Biological Revolution*, op. cit., (note 153) pp. 80-93; Richard A. McCormick, "Notes on Moral Theology", *Theological Studies*, 37, (3) (1976), pp. 100-107; Gilbert Meilander, "Killing and Allowing to Die", *Theological Studies* 37 (3), 1976, 467-470; P. J. Fitzgerald, "Acting and Refraining", *Analysis*, 27,4, March 1967, pp. 133-139.
183. Childress, James, op. cit., (note 182), p. 3.

That is, once motives are put aside we might find morally relevant distinctions in their actions and omissions on the basis of other factors such as duty to act, methods used and so forth. Put in terms of a simple statement, as applicable in law as in morals, one might then express it this way: If there is no difference between killing and allowing to die, it is because one has a duty not to allow to die; but if there is *no* such duty then there is a difference between them because there *is* a duty not to kill. P. J. Fitzgerald (op. cit., note 182) expresses the same point in this manner: "This then points to one moral difference between acting and not-acting, where both will cause harm. Acting seems to start with a presumption against it: *e.g.* killing is *prima facie* wrong. Not-acting starts without any such presumption, and it is only by establishing a duty to act that we show that not-acting is wrong. Killing needs to be justified; not saving life does not." (p. 136)

184. Childress, James, op. cit., (note 182), p. 4.
185. Fletcher, Joseph, "The Right to Live and the Right to Die", op.cit., (note 173) p. 14.
186. Ramsey, Paul, *The Patient as Person*, op. cit., (note 90) p. 153.
187. Beauchamp, Tom L., "A Reply to Rachels on Active and Passive Euthanasia", op. cit., (note 182) p. 71.

See also Sissela Bok, who notes that even, "The provision that the patient be dying . . . is not without ambiguity. In a sense, any patient who is seriously ill might or might not be dying. And even in these cases where death seems *likely* in days or weeks, its probability varies. Thus one patient may be thought of as having one chance in a hundred of surviving, the estimate based on a comparison with past cases. Another may be considered to have two chances in a hundred, or five, of surviving. Where does one draw the line and determine that the patient is definitely dying? Nowhere in the long history of disagreement among doctors about the certainty of the prognosis of death has this question been resolved." From "Euthanasia and the Care of the Dying", in John

A. Behnke and Sissela Bok (editors), *The Dilemmas of Euthanasia*, Anchor Books, Doubleday, N.Y., 1975, p. 3." See also Brown, Norman *et al.*, "The Preservation of Life", *Journal of the American Medical Association*, 21, 1970, 76-81.

188. Veatch, Robert, *op. cit.*, (note 153) p. 89.

189. Bok, Sissela, "Euthanasia and the Care of the Dying", *op. cit.*, (note 187), p. 8.

It is of course impossible and unnecessary to deny that in many *individual cases* it may well be more "humane" not simply to cease treatment, but to actively hasten death. Referring to babies born with spina bifida, and to programs (such as those of Dr. John Lorber) which select for treatment those newborns with the best prognoses, while allowing those with no chance for "normal" lives to die, one commentator writes, "There is a blatant inconsistency in the attitudes of doctors who operate a policy of 'selection'. The whole aim of such a policy, and the hope of all those who are a party to the decision to put that policy into operation, is that the child should be allowed to die quickly. Yet, having made this selection, the same doctors, along with the baby's parents, are prepared, or are forced, to stand back, take no further action, and watch the child take three, six or sometimes as many as nine months to die. In the most unfortunate of circumstances the child will live on, either in an institution, or cared for by its parents . . . The state of affairs is clearly ironical, and verges on the hypocritical. If a designated aim of medicine is that a child should die, why would it not be more humane to make it die?" Robert Reid, "Spina Bifida: The Fate of the Untreated", *Hastings Center Report*, Aug. 1977, p. 18.

190. Beauchamp, Tom L., *op. cit.*, (note 182) p. 73.

191. Louisell, David, "Euthanasia and Biathanasia: On Dying and Killing", *Linacre Quarterly* 40: 234-258, 1973.

192. Though others argue that the burden of proof should be on those opposing legalization to show that euthanasia is wrong. One of these is Anthony Flew, who writes that the proper question is not, "Why should people be given this new legal right?", but, "Why should people in this matter be restrained by law from doing what they want?" While I disagree with Flew as to which side has the burden of proof, I hope the reasons given above provide adequate answers to his question.

193. On the art of pain control see for instance Cicely Saunders, "The Challenge of Terminal Care", in T. Symington and R. L. Carter (editors), *Scientific Foundations of Oncology*, William Heinemann Medical Books Ltd., London, pp. 673-679; Twycross, R. G. "Diseases of the Central Nervous System: Relief of Terminal Pain", *British Med. Journal* 4: 212, 1975.

It should however be noted that the word (and reality of) pain is considerably more ambiguous, less objectifiable and more multi-faceted than medical journal articles usually acknowledge. "Pain control" is no

doubt a highly advanced art insofar as the target is limited to bodily pain accessible to pain-killing drugs or surgical intervention. But "pain" in other senses is not so objectifiable or manageable. At one level it is a problem of language, as noted for instance by Ivan Illich. "The technical matter which contemporary medicine designates by the term pain even today has no simple equivalent in ordinary speech. In most languages the term taken over by the doctors covers grief, sorrow, anguish, shame and guilt . . ." (*Medical Nemesis*, McClelland and Stewart, Toronto, 1975, p. 97).

Illich has much of interest and relevance to say about the history and "cultural framework" of pain. He notes for instance that, "As long as pain was primarily an experience that had to be faced and suffered, its political function was to set limits to man-made abuses of man by man when these became intolerable. Now an increasing portion of all pain is man-made, a side effect of strategies for industrial expansion . . . the industrial system responds by delivering them medical pain-killers. Pain thus turns into a demand for more drugs, hospitals, medical services . . . no matter what its human, social or economic cost." (p. 94.).

194. Childress, James, op. cit., (note 182) p. 9.
195. Ramsey, Paul, *The Patient as Person*, op. cit., (note 90) pp. 160-164.
196. Ibid., p. 161.
197. Veatch, Robert, op. cit., (note 153) p. 95.
198. Hare, R. M., "Abortion and the Golden Rule", *Philosophy and Public Affairs*, vol. 4, No. 3, Spring 1975, pp. 202-203.
199. Fletcher, Joseph, "The 'Right' to Live and the 'Right' to Die: a Protestant View of Euthanasia", op. cit., (note 173) p. 12.
200. Hauerwas, Stanley, "Rights, Duties and Experimentation on Children: A Critical response to Worsfold and Bartholome", in *Appendix to Research Involving Children*, The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, DHEW Publication no. (05) 77-0005, Washington, D.C. 1977, pp. 5-1 to 5-27, 1977.
201. Particularly in two unpublished papers, "The Definition of Death and the Right to Die" (1976) and "Legalism and Medical Ethics" (1977), and as presented by him in a public lecture during the "Colloquium on Biomedical Ethics", London, Ont., Oct. 27-30, 1977.
202. That there is in fact a difference between the perspectives of law and morals is of course one of the theses of this section of the paper. But an observation made in the Introduction (p. 1) should be recalled here. On the one hand, a judgment about morals is a necessary condition (at least psychologically) for law and punishment to be brought into play. Especially with criminal law one wants to think that the law is making a *moral* claim, and not just a legal claim on one. But on the other hand, a judgment about morals is not a *sufficient* condition. The acts in question

might not be sufficiently harmful; (or) if harmful, the law and legal processes may not be the best means of dealing with them.

203. Ladd, John, "Legalism and Medical Ethics", op. cit., (note 201), p. 7.

See also for instance David Mechanic, "Health and Illness in Technological Societies", *Hastings Center Studies*, 1, 3, 1973, 7-18. He notes that in view of the growing bureaucratization and depersonalization of medicine as an institution, the traditional responses of formulating rules on an *ad hoc* basis, or relying largely on informal solutions out of sight of the public forum are no longer adequate. "Traditionally, we have seen many of the dilemmas as problems to be worked out by patients and their individual physicians in their continuing relationship which was viewed as confidential and intimate. But medicine is now more complex; physician services are more specialized, stratified, and segmented, and a wide variety of non-medical personnel plays an important role in the delivery of patient care . . . The thrust of organizational events is to encourage bureaucratic solutions to the uncertainties and complexities of a changing technology. But, at the same time, people in modern societies are seeking greater autonomy over decisions affecting their own lives." (p. 14)

204. Ladd, John, *Ibid.*, p. 8.

205. This point of course assumes that rules express and articulate rights, or that rights in a sense represent rules (see Ladd, *Ibid.*, p. 9).

206. *Ibid.*, p. 15.

207. For more on this Movement see: "St. Christopher Hospice", *Nursing Times*, July 28, 1967, pp. 2-5; Saunders, Cicely, "When a Patient is Dying", *Nursing Times*, Nov. 13, 1959, pp. 1129-1130; Saunders, Cicely, *Care of the Dying*, Macmillan, London, 1959; Garner, Jim, "Palliative Care: it's the quality of life remaining that matters", *Canadian Medical Association Journal*, 115, July 17, '76, pp. 179-180; Paige, Roberta Lyder; Looney, Jane Finkbiner, "Hospice Care for the Adults", *American Journal of Nursing*, Nov. 1977, pp. 1812-1815.

208. See for instance these writings by Kübler-Ross: *On Death and Dying*, Macmillan, N.Y., 1969; "Dying with Dignity", *The Canadian Nurse*, 67, 10 (Oct. 1971), pp. 31-35; "The Family Physician and the Dying Patient", *Canadian Family Physician* (Oct. 1972), pp. 79-83; *Death the Final Stage of Growth*, Prentice Hall, Englewood Cliffs, N.J., 1975.

209. Ladd, John, "Legalism and Medical Ethics", op. cit., p. 15.

It is sometimes argued or suggested that in today's impersonal, complex and highly technical medical bureaucracy qualities such as compassion are more or less secondary and a luxury compared to the need to secure rights in formal structures and processes. Yet even one who could be linked with aspects of that view acknowledges that, "It is ironic that now that medicine has developed the capacity to be helpful in a variety of ways, it has lost much of its capacity to communicate compassion, so

central to the healing process. Indeed, even from a purely technical perspective, the effectiveness of medical care depends on the patient's cooperation . . . Failures in communication and empathy not only harm a vital function of medical care, but also diminish the opportunities for technical quality and effectiveness." David Mechanic, *op. cit.*, (note 203), p. 9.

210. See Urmson, J. O., "Saints and Heroes", in Joel Feinberg (ed.) *Moral Concepts*, London: Oxford University Press, 1961, pp. 60-73. (Cited by Ladd, *op. cit.*, p. 17).
211. Ladd, John, "Legalism and Medical Ethics", *op. cit.*, p. 18.
212. *Ibid.*, p. 21.
213. *Ibid.*, p. 25.
214. Burt, Robert A., "The Limits of Law in Regulating Health Care Decisions", *Hastings Center Report*, 7, 6, Dec. '77, p. 29. The analysis which follows on the subject of "objectivity" and "detachment" is largely based on Burt's.
215. *Ibid.*, p. 30.
216. *Ibid.*, p. 30.
217. *Ibid.*, p. 32.
218. *Ibid.*, p. 32.
219. John Ladd (in his "The Definition of Death and the Right to Die", *op. cit.*, p. 14) gives the name "ideal rights" to what for instance H. J. McCloskey calls, "welfare rights". See J. J. McCloskey, "Rights", *Philosophical Quarterly* 15 (1965), pp. 115-127.
220. Ramsey, Paul, "Euthanasia and Dying Well Enough", *op. cit.*, (note 146) p. 45.
221. See, *New England Journal of Medicine*, 295, August 12, 1976. Rabkin, Mitchell *et al.*, "Orders not to Resuscitate", p. 364, Pontoppiden, H. *et al.*, "Optimum Care for Hopelessly Ill Patients", p. 362.
222. Fried, Charles, "Terminating Life Support: Out of the Closet", *New England Journal of Medicine* 295, Aug. 12, 1976, p. 390.
223. It should be noted that a great number of hospitals, intensive care units, palliative care units or other groups attached to hospitals are presently working on such guidelines. In Canada one such group I am aware of is the Medical/Legal/Theological Society, composed largely of physicians, nurses and chaplains attached to Foothills Hospital in Calgary, Alberta. Another is a group of staff members attached to McMaster University Medical Centre, in Hamilton, Ontario.
224. Fried, Charles, *op. cit.*, p. 390.

225. Shannon, Thomas A., "What Guidance from the Guidelines"? *Hastings Center Report*, 7, 3, June 1977, p. 30.
226. *Ibid.*, p. 30.
227. Culliton, Barbara J., "Helping the Dying Die: Two Harvard Hospitals Go Public with Policies", *Science*, 193, 17 Sept. 1976, pp. 1105-1106.
228. *Superintendent of Belchertown State School vs. Saikewicz*, Massachusetts Supreme Judicial Court No. 51C-711, 1977.
229. As regards competent patients, the U.S. decision which set the standard for refusal of treatment (in the context of informed consent) was a 1960 decision by the Kansas Supreme Court:

Anglo-American law starts with the premise of thorough-going self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery or other medical treatment. A doctor might well believe that an operation or form of treatment is desirable or necessary but the law does not permit him to substitute his own judgment for that of the patient by any form of artifice or deception (*Natanson v. Kline*, 186 Kan. 393, 350 P. 2d, 1093 [1960]).

This right for competent patients is equally clear in Canada. See *Marshall v. Curry* (1933) 3 D.L.R. 260 (N.S.S.C.).

230. For more on this point see the detailed and insightful study by Paul Ramsey, "The *Saikewicz* Precedent: What's Good for an Incompetent Patient?", *Hastings Center Report*, 8, 6, (Dec. 1978) pp. 36-42. Ramsey notes that, "... we may ask whether the court in reaching for grounds for its substituted judgment did not exceed its grasp. In substituting judgment for this never-competent patient, it set aside the standard of a normal child patient, who also cannot understand the pain and would have to be restrained during prolonged treatment. Attempting to get at Saikewicz's 'subjective' standard, I shall suggest, the court treated him *as if* he were a competent patient who then would 'reasonably' take into account the fact that he was incompetent!" (p. 36). Later Ramsey adds, "This quest [of the court's, i.e. to bring the substituted judgment into step with the value and desires of the affected individual] means that the substituted judgment must necessarily be the court's subjectivity, little or not at all constrained by proposed objective tests. Joseph Saikewicz's 'subjectivity' was not *found* by any test the court thought pertinent." (p. 39).

Ramsey rightly observes that, "*Ascription*, not *discovery* of an interest in the incompetent whose case is before the court becomes the meaning of the substituted judgment doctrine." (p. 37). He goes on to add that the question as to what Saikewicz would have decided is an improper question because the court's substituted judgment is not anchored in an *objective* finding or discovery about that incompetent patient. (see his note 6).



231. Curran, William J., "The Saikewicz Decision", *New England Journal of Medicine*, March 2, 1978, p. 500.
232. Annas, George, "The Incompetent's Right to Die: the Case of Joseph Saikewicz", *Hastings Center Report*, 8, 1, Feb., 1978, p. 23.

On the other hand, in fairness to Annas we should note that elsewhere ("After Saikewicz: No Fault Death", *Hastings Center Report*, 8, 3, June '78, 16-18) he maintains that the scope of the Saikewicz case is much narrower and more specific than many of those hostile to it realize. In his view, "The scope of the case is properly limited to the incompetent patient (adult or child) for whom a *life-prolonging treatment is available* that is used on some patients as *standard medical procedure* and that is opposed by both the family and the physician because they do not believe the treatment is in the best interests of the patient (p. 17)." In such cases the patients are not terminally ill, and further treatment is not futile, but discontinuing treatment is being considered, ". . . because the physician and family do not believe that the patient's 'quality of life' justifies further treatment . . . (p. 17)." The real issue in these cases (he argues) is not really "medical" at all, and therefore ought to be resolved in courts of law. Cases which remain for the physician to resolve and act upon without resorting to the courts are those involving the discontinuing of treatment for the *terminally ill*. Since there has *never* been a criminal indictment for discontinuing treatment of a terminally ill adult, and since under the circumstances, the only important question is prognosis and feasible treatments, the risk of prosecution is almost nonexistent and the questions are medical in nature. Accordingly, I would argue that it is the physician's duty as a professional to make such determinations (but only with consent if the patient is competent) and act upon them without seeking immunity (p. 17)."

Annas may well be correct in his analysis of the real scope of the Saikewicz case, but I am not convinced that cases and decision making can be as neatly and as hermetically categorized into either "properly medical" decisions if the patient is terminally ill, or "non-medical" decisions if the issue turns (partly) on quality of life factors. The thrust of my own argument has been that there is a very large medical and "non-subjective" quotient involved even in quality of life decision making and the application of factors such as prognosis, patient's perspective, patient's benefit and "reasonable person" judgment.

233. Curran, William, op. cit., (note 231) p. 500.
234. Relman, Arnold S., (M.D.), "The Saikewicz Decision: Judges as Physicians", *The New England Journal of Medicine*, March 2, 1978, p. 508.

Such fears may not be exaggerated in the light of the fact that six cases have been heard by Massachusetts courts in the wake of the Saikewicz decision in the roughly six month period between the decision (November 1977) and June 1978. Annas may be correct when he notes (in, "After Saikewicz: No Fault Death", see note 232 above) that only

one of those six cases is the type of case the Court was thinking of. Nevertheless the other cases were in fact heard by the courts as well, and an unhealthy climate of hostility and fear has clearly taken root in that jurisdiction and elsewhere as a result of the Saikewicz decision.

235. The group met in California and brought together 20 persons from various disciplines: medical, nursing, law, sociology, ethics, economics, social work, anthropology and the news media. See A. R. Jonsen *et al.*, "Critical Issues in New-born Intensive Care: A Conference Report and Policy Proposal", *Pediatrics* 55, 6, June 1975, pp. 756-768.
236. *Ibid.*, p. 760.
237. It should be recalled here that the court in the Saikewicz case professed the opposite view, namely that quality of life concerns should *not* be weighed by the courts, except in the matter of pain.
238. Jonsen (*et al.*), *op. cit.*, p. 762.
239. *Ibid.*, p. 762.
240. See James W. Haviland, "Experiences in Establishing a Community Artificial Kidney Center", *Transactions of the American Clinical and Climatological Association* 77, (1961), pp. 133-34; Sanders, David and Dukeminier, Jesse, "Medical Advance and Legal Lag: Hemodialysis and Kidney Transplantation", *UCLA Law Review*, 15 (1968) especially pp. 371-386; Ramsey, Paul, *The Patient as Person*. Yale U. Press, New Haven, 1970, chapter 7, "Choosing How to Choose: Patients and Sparse Medical Resources", *espec.* pp. 242-259; Reiser, Stanley Joel (M.D.), "Therapeutic Choice and Moral Doubt in a Technological Age", *Daedalus*, 3, 106, Winter 1977, especially pp. 53-55. See also, Katz, Al, "Process Design for Selection of Hemodialysis and Organ Transplant Recipients", *Buffalo Law Review*, 21, 1972, pp. 373-418; Buxton, M. J., "Cost-Benefit Analysis of Long-Term Haemodialysis for Chronic Renal Failure", *British Medical Journal*, 17 May, 1975, pp. 376-379.
241. Haviland, James W., *op. cit.*, (note 240) pp. 133-34.
242. Sanders, David and Dukeminier, Jesse, *op. cit.*, (note 240) p. 378.
243. Ramsey, Paul, *op. cit.*, (note 240) p. 256.
244. *Ibid.*, p. 259.
245. Fuller, L., *The Morality of Law* (revised edition), Yale U. Press, New Haven, 1969, p. 12.
246. This latter view is particularly that of Edmond Cahn in his discussion of the case of *United States v. Holmes* in his, *The Moral Decision: Right and Wrong in the Light of American Law*, Indiana U. Press, Bloomington, 1955, pp. 61-71. For a refutation of this "method", see Ramsey, *The Patient as Person*, pp. 259-266.
247. Ramsey, Paul, *op. cit.*, (note 240) p. 253.

248. Nader, Dr. Laura, "Personal communication", in A. R. Jonsen (*et al.*), "Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal", *op. cit.*, (note 235) p. 760.

Whether Dr. Nader is aware of it or not, much of her observation raises the difficult medical/ethical problem of "statistical lives". That is, if resources allocated to life saving should be used so as to maximize the number of lives saved, or minimize the number of lives lost, then, a cost-benefit analysis typical of economists would say that there is an apparent anomaly in our readiness to expend far more resources saving lives of *known persons in present peril* than on measures to prevent future perils for those unknown. For a helpful treatment of this problem, see Charles Fried, "The Value of Life", *Harvard Law Review*, 82(7):1415-1437, May 1969. He argues that there are important values to consider beyond simple life maximization, and that we have obligations to the presently dying even if the expenditure of resources will not in the long run lead to minimizing the number of lives lost. See also note 252 below.

249. Ramsey, Paul, *op. cit.*, (note 240) p. 274.
250. Jonsen, A. R., *op. cit.*, (note 235) p. 763.
251. Ramsey, Paul, *op. cit.*, (note 240) p. 272.
252. Writing of the cost-benefit analysis applied to the issue of genetic quality of life, Daniel Callahan writes, "We can now, quite literally, put a price on everyone's head, working out the long-term financial costs to individuals and societies of caring for a defective child. But observe a curiosity. It was counted a great advance of the modern mind when a bookkeeping God, with his minutely maintained ledger of good and bad deeds, was noisily rejected. Yet here we are beginning to keep our own books . . . we seem to have forgotten why the bookkeeping God was rejected—because it seemed eminently unjust, insensitive and outrageous that a score card be kept on human lives. Indeed we are even worse than that old God; for at least in his ledger everything was supposedly recorded. But our cost-benefit analysis totes up only one item—what the financial liability will be . . . the kind of cost-benefit analysis which seems to be emerging in genetic calculations goes only in the *cost* direction. It is seemingly assumed that the benefits to a society which decided simply to bear the costs of humane care are either non-existent or simply too intangible to be worth much bother". ("The Genetic Quality of Human Life", in his *The Tyranny of Survival and Other Pathologies of Civilized Life*, Macmillan, N.Y., 1978, p. 226).
253. The otherwise excellent policy paper of Health and Welfare Canada, "A New Perspective on the Health of Canadians" by Marc Lalonde (published in 1974) is a not untypical example of a health policy paper with very few clues on how priorities for the health dollar are established, or what the various implications of policy choices are for *other* medical services and the wider societal context.

254. Ramsey, Paul, *op. cit.*, p. 274.

255. Bok, Sissela, *New England Journal of Medicine*, Aug. 12, 1976. A number of organizations have distributed other versions of living wills. One version (which refers somewhat vaguely to "physical or mental disability"), is that of the Euthanasia Education Council. Another (somewhat strangely entitled, "Christian Affirmation of Life"), is that of the Catholic Hospital Association (U.S.). This latter is largely a request for prayers and a profession of faith, reserving only a few lines for a request that if there is no reasonable hope of recovery from "physical and mental disability", no extraordinary means be used.
256. For the background and evolution of this Bill, see Michael Garland, "The Right to Die in California—Politics, Legislation and Natural Death", *Hastings Center Report*, Oct. 1976, pp. 5-6.
257. McCormick, Richard, and Hellegers, André, "Legislation and the Living Will", *America*, March 12, 1977, p. 211.
258. The Quinlan case offers a good example of this shift in the doctor/patient relationship away from the patient/family to the physician as primary decision-maker. As McCormick-Hellegers note *op. cit.*, p. 211), it was Mr. Quinlan who went to court to have his request upheld, and not the physician who went to court to have that request denied, the presumption being that physicians have a right to treat a patient unasked and even opposed.
259. Veatch, Robert, "Death and Dying: The Legislative Options", *Hastings Center Report*, Oct. 1977, p. 6.
260. Lebacqz, Karen, "Commentary on Natural Death", *Hastings Center Report*, April, 1977, p. 14.
261. See for instance, Kübler-Ross, *On Death and Dying*, Macmillan, N.Y., 1969; Glaser, B. G. and Strauss, A. L., *Awareness of Dying*, Aldine, Chicago, 1965.
262. See for instance Diana Crane, *The Sanctity of Social Life: Physicians' Treatment of Critically Ill Patients*, Russell Sage Foundation, N.Y., 1975, espec. pp. 46-52, 78-89. See also her "Physicians' Attitudes Toward the Treatment of Critically Ill Patients", *Bioscience*, Vol. 23, August 1973, p. 474.
263. *Ibid.*, and see also for instance a poll conducted by the American Medical Association, in the *A.M.A. News*, Jan. 24, 1977, as cited by McCormick-Hellegers, *op. cit.*, p. 213. Nurses, as well, appear to respect patient wishes in this regard. See, *Nursing*, Vol. 5, No. 10, Oct. 1975, p. 42. See also, "Physicians Attitude Survey: Doctors and Dying, Is Euthanasia Now Becoming Accepted?", *Medical Opinion*, May 1974, p. 32. Regarding Canadian doctors specifically, see "Euthanasia, 1,700 Doctors Speak Out", *Modern Medicine of Canada*, Vol. 29, No. 7, July 1974, p. 660.
264. *Ibid.*, (notes 262 & 263). See also, A. S. Kraus, *Survey of Health Care Professionals Concerning their Experience with, and Opinions regard-*

*ing. Adult Patients who want to die*, Queens University at Kingston, Ontario, Dept. of Community Health and Epidemiology, 1977.

265. McCormick and Hellegers, *op. cit.*, (supra, note 257) p. 213.
266. Burt, R. A., "Authorizing Death for Anomalous Newborns", in Aubrey Milunsky and George J. Annas, *Genetics and the Law*, Plenum Press, N.Y., 1976, p. 445, as cited by G. Annas in "After Sailewicz: No Fault Death", see above note 232.

## Selected Bibliography

- AIKEN, Henry David. *Reason and Conduct*, Alfred A. Knopf, N.Y., 1962.
- "Life and the Right to Life", in James M. Humber and Robert F. Almeder, *Biomedical Ethics and the Law*. Plenum Press, N.Y., 1976, 465-475.
- ANNAS, George T., "Decision-Making and the Critically Ill Patient: Some Legal Aspects of a Patient Classification Scheme". *Linacre Quarterly*, 42,2 (May 1975), 116-122.
- "The Incompetent's Right to Die: The Case of Joseph Saikewicz", *Hastings Center Report*, 8,1 (Feb. 1978), 21-23
- "After Saikewicz: No Fault Death", *Hastings Center Report*, 8,3 (June 1978), 16-18.
- BAIER, Kurt, "The Sanctity of Life", *Journal of Social Philosophy*, 5,2 (April 1974), 1-11.
- "Towards a Definition of Quality of Life", in Peter C. List and Ronald O. Clarke (editors), *Environmental Spectrum*, D. van Nostrand Co., N.H., 1974.
- BEAUCHAMP, Tom L., "A Reply to Rachels on Active and Passive Euthanasia", *Social Ethics*, McGraw Hill, 1977, 67-74.
- BEAUCHAMP, Tom L., and WALTERS, LeRoy (editors), *Contemporary Issues in Bioethics*, Dickenson Publishing Co. Inc., Encino, Calif., 1978.
- BEHNKE, John A., and BOK, Sissela, *The Dilemmas of Euthanasia*. Anchor Books, Doubleday, N.Y., 1975.
- BERMAN, Harold J., *The Interaction of Law and Religion*, Abingdon Press, N.Y., 1974.
- OLACK, Peter McL., "Brain Death", *New England Journal of Medicine*, 299,7 (August 17, 1978), 338-344; 299,8 (August 24, 1978), 393-404.
- BOK, Sissela, "Who Shall Count as a Human Being? A Treacherous Question in the Abortion Discussion", in Robert L. Perkins (ed.), *Abortion Pro and Con*, Shenkman, Cambridge, Mass. 1974, 91-105.

- BONHOEFFER, D., *Letters and Papers from Prison*, Macmillan, N.Y., 1962.
- BURT, Robert A., "The Limits of Law in Regulating Health Care Decisions", *Hastings Center Report*, 7,6 (Dec. 1977), 29-32.
- CALLAHAN, Daniel, "The Sanctity of Life", in Donald R. Cutler (ed.), *Updating Life and Death*. Beacon Press, Boston, 1968.
- *The Tyranny of Survival and other Pathologies of Civilized Life*, Macmillan, N.Y., 1973.
- CAPRON, Alexander M., and KASS, Leon R., "A Statutory Definition of the Standards for Determining Human Death: An Appraisal and a Proposal", *U. of Pennsylvania Law Review*, 121,1 (Nov. 1972), 87-118.
- CLOUSER, K. Danner, "The Sanctity of Life: An Analysis of a Concept", *Annals of Internal Medicine* 78: 119-125, 1973.
- CRANE, Diana, "Physicians' Attitudes Toward the Treatment of Critically Ill Patients", *Bioscience*, 23,8 (August 1973), 471-474.
- *The Sanctity of Social Life: Physicians' Treatment of Critically Ill Patients*, Russell Sage Foundation, N.Y., 1975.
- CURRAN, William J., "The Saikewicz Decision", *New England Journal of Medicine*, 298,9 (March 2, 1978), 499-500.
- DIAMOND, Eugene F., "Quality vs. Sanctity of Life in the Nursery", *America*, 135, (Dec. 4, 1976), 396-398.
- DILLMAN, Donald A., and TREMBLAY, Kenneth R., "The Quality of Life in Rural America", *The Annals of the American Academy of Political and Social Science*, 429 (Jan. 1977), 115-129.
- ENGELHARDT, H. T., "The Beginning of Personhood: Philosophical Considerations", *Perkins Journal*, 27,2 (Fall 1973), 20-27.
- "The Counsels of Finitude", in Peter Steinfeld and Robert Veatch (editors), *Death Inside Out*, Harper and Row, N.Y., 1973, 115-125.
- "Medicine and the Concept of Person", (unpublished paper), Kennedy Institute and Dept. of Philosophy, Georgetown U., Wash., D.C., Nov. 19, 1974.
- "Bioethics and the Process of Embodiment", *Perspectives in Biology and Medicine*, 18,4 (Summer 1975), 486-500.
- FEINBERG, Joel, *Doing and Deserving: Essays in the Theory of Responsibility*, Princeton U. Press, Princeton, N.J., 1974.
- FITZGERALD, P. J., "Acting and Refraining", *Analysis*, 27,4 (March, 1967), 133-139.
- FLAHIFF, Cardinal George, "The Church and Life Support Systems" *The Catholic Register*, Oct. 29, 1977.
- FLETCHER, George P., "Prolonging Life: Some Legal Considerations", *Washington Law Review*, 42(1967), 999-1016.
- FLETCHER, Joseph, "The Right to Die", *Atlantic Monthly*, April 1968, p. 64.

- "Indicators of Humanhood: A Tentative Profile of Man", *Hastings Center Report*, 2,5 (Nov. 1972), 1-4.
- "The Right to Live and the Right to Die", *The Humanist*, 34,4 (July-August, 1974), 12-15.
- "Four Indicators of Humanhood—the Enquiry Matures", *Hastings Center Report*, 4,6 (Dec. 1974), 4-7.
- FLEW, Antony, *Body, Mind and Death*, Macmillan, N.Y., 1964.
- FOOT, Philippa, "Euthanasia", *Philosophy and Public Affairs*, 6,2 (Winter 1977), 85-112.
- FRIED, Charles, "An Analysis of 'Equality' and 'Rights' in Medical Care", *Hospital Progress*, 57 (Feb. 1976), 44-49.
- "Terminating Life Support: Out of the Closet", *New England Journal of Medicine*, 295,7 (12 Aug. 1976), 390-391.
- GARLAND, Michael, "The Right to Die in California—Politics, Legislation and Natural Death", *Hastings Center Report*, 6,5 (Oct. 1976), 5-6.
- GARNER, Jim, "Palliative Care: it's the quality of life remaining that matters", *Canadian Medical Association Journal*, 115 (July 17, 1976), 179-180.
- GOROVITZ, Samuel (*et al.*, editors), *Moral Problems in Medicine*, Prentice Hall, Englewood Cliffs, N.J., 1976.
- GUSTAFSON, James N., "Basic Ethical Issues in the Biomedical Fields", *Soundings*, 53 (Summer 1970), 151-180.
- "The Contributions of Theology to Medical Ethics" *Perspectives in Biology and Medicine*, 19,2 (Winter 1976) 247-270.
- HARRISON, C.P., "Medicine, Terminal Illness and the Law", *Canadian Medical Association Journal*, 117 (September 3, 1977), 514-519.
- HAUERWAS, Stanley, "The Retarded and the Criteria for the Human", *Linacre Quarterly*, 40,4 (Nov. 1973), 217-222.
- "Must a Patient be a 'Person' to be a Patient?" *Connecticut Medicine*, 39,12 (Dec. 1975), 815-817.
- HIGH, Dallas, "Is 'Natural Death' an Illusion?", *Hastings Center Report*, 8,4 (August 1978), 37-42.
- JONSEN, A. R. (*et al.*) "Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal", *Pediatrics*, 55,6 (June, 1975), 756-768.
- JONSEN, Albert R. and JAMETON, Andrew L., "Social and Political Responsibilities of Physicians", *The Journal of Medicine and Philosophy*, 2,4 (Dec. 1977), 376-400.
- JONSEN, Albert R. and LISTER, George, "Newborn Intensive Care: The Ethical Problems", *Hastings Center Report*, 8,1 (February 1978), 15-18.
- KING-FARLOW, John and SHEA, William R. (editors), *Values and the Quality of Life*. Canadian Contemporary Philosophy Series, Science History Publications, N.Y., 1976.



- KLUGE, Eike-Henner, W., *The Practice of Death*, Yale U. Press, New Haven and London, 1975.
- "The Right to Life of Potential Persons", *Dalhousie Law Journal*, Jan. 1977, 837-848.
- KOHL, Marvin, *The Morality of Killing*, Humanities Press, Atlantic Highlands, N.J., 1974.
- (ed), *Beneficent Euthanasia*, Prometheus Books, N.Y., 1975.
- KÜBLER-ROSS, E., *On Death and Dying*, Macmillan, N.Y., 1969.
- *Death—The Final Stage of Growth*, Prentice-Hall, Englewood Cliffs, N.J., 1975.
- LADD, John, "Legalism and Medical Ethics" (unpublished).
- "The Definition of Death and the Right to Die (unpublished).
- LALONDE, Marc, *A New Perspective on the Health of Canadians*, Information Canada, Ottawa, 1975.
- LAW REFORM COMMISSION OF CANADA
- *Cessation of Treatment and Euthanasia*, Working Paper, forthcoming, Fall 1979.
- *Criteria for the Determination of Death*, Working Paper, 1979.
- *Treatment in Criminal Law*, Working Paper, forthcoming, Fall, 1979.
- LOUISELL, David, "Euthanasia and Biathanasia: On Dying and Killing", *Linacre Quarterly*, 40,4 (Nov. 1973), 234-258.
- MCCORMICK, Richard A., "To Save or Let Die: the Dilemma of Modern Medicine", *Journal of the American Medical Association*, 229,2 (8 July 1974), 172-176.
- "A Proposal for 'Quality of Life' Criteria for Sustaining Life", *Hospital Progress*, 56,9 (Sept. 1975), 76-79.
- MCCORMICK, R. and HELLEGERS, A., "Legislation and the Living Will", *America*, (March 12, 1977), 210-213.
- MCCORMICK, R., "The Quality of Life, the Sanctity of Life", *Hastings Center Report*, 8,1 (Feb. 1978) 30-36.
- MASLOW, Abraham, *Motivation and Personality*, N.Y., 1954.
- MECHANIC, David, "Health and Illness in Technological Societies", *Hastings Center Studies*, 1,3,1973, 7-18.
- METZ, Johannes, *Theology of the World*, Seabury Press, N.Y., 1973.
- MORRISON, Robert S., "The Dignity of the Inevitable and Necessary", in Peter Steinfelds and Robert Veatch (editors), *Death Inside Out*, Harper and Row, N.Y., 1974, 97-100.
- RACHELS, James, "Active and Passive Euthanasia", *The New England Journal of Medicine*, 292 Jan. 9, 1975, 78-80.
- RAHNER, Karl, "Experiment Man", *Theology Digest*, (Feb. 1968), 57-69.

- RAMSEY, Paul, *The Patient as Person*, Yale University Press, New Haven and London, 1970.
- “The Indignity of ‘Death with Dignity’”, in Peter Steinfeld and Robert Veatch (editors), *Death Inside Out*, Harper and Row, N.Y., 1974, 81-96.
- “Prolonged Dying: Not Medically Indicated”, *Hastings Center Report*, 6,1 (Feb. 1976), 14-17.
- “Euthanasia and Dying Well Enough”, *Linacre Quarterly* 44,1 (Feb. 1977), 37-46.
- “The Saikewicz Precedent: What’s Good for an Incompetent Patient?”, *Hastings Center Report*, 8, 6 (Dec. 1978), pp. 36-42.
- ST. JOHN-STEVAS, Norman, *The Right to Life*, Holt, Rinehart and Winston, New York, 1963.
- SANDERS, David and DUKEMINIER, Jesse, “Medical Advance and Legal Lag: Hemodialysis and Kidney Transplantation”, *UCLA Law Review*, 15 (1968), 357-413.
- SAUNDERS, C., *Care of the Dying*, Macmillan, London, 1959.
- “The Challenge of Terminal Care”, in T. Symington and R. L. Carter (editors), *Scientific Foundations of Oncology*, William Heinemann Medical Books Ltd., London, 1976, 673-679.
- SHAW, Anthony, “Defining the Quality of Life”, *Hastings Center Report*, 7,5 (Oct. 1977), 11.
- SHILS, Edward, “The Sanctity of Life”, in Daniel H. Labby (ed.), *Life or Death: Ethics and Options*, U. of Wash. Press, Seattle, 1968, 2-38.
- STARKMAN, Bernard, “The Control of Life: Unexamined Law and the Life Worth Living”, *Osgoode Hall Law Journal*, 11,1 (June 1973), 175-185.
- STORCH, Janet L., *Consumer Rights and Nursing*, U. of Alberta, Edmonton, 1977.
- SUMNER, L. W., “A Matter of Life and Death”, *Noûs* 10 (1976), 145-171.
- TAUBENFELD, Howard, J., “The Beginnings of Personhood: Legal Considerations”, *Perkins Journal*, (Fall 1973), 16-19.
- TOOLEY, Michael, “A Defence of Abortion and Infanticide”, in Joel Feinberg (ed.), *The Problem of Abortion*, Wadsworth Pub. Co., Belmont, Calif. 1973, 51-91.
- VAUX, Kenneth (ed.) *Who Shall Live? Medicine, Technology, Ethics*, Fortress Press, Philadelphia, 1970.
- VEATCH, Robert M., “The Whole-Brain Oriented Concept of Death: An Outmoded Philosophical Formulation”, *Journal of Thanatology*, 3,13 (1975), 13-30.
- *Death, Dying and the Biological Revolution*, Yale University Press, New Haven and London, 1976.
- “Death and Dying: The Legislative Options”, *Hastings Center Report*, 7,5 (Oct. 1977), 5-8.

- WEBER, Leonard J., *Who Shall Live?*, Paulist Press, N.Y., 1976.
- WEILER, Karen M. and COTTON, Kathleen, "The Unborn Child in Canadian Law", *Osgoode Hall Law Journal*, 14,3 (Dec. 1976), 643-659.
- WICKER, Brian, *Culture and Theology*, Sheed and Ward, London, 1966.
- WILLIAMS, Granville, *The Sanctity of Life and the Criminal Law*, Faber and Faber Ltd., London, 1958.