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The Sanctity of Life, the Quality of Life and the New ‘Baby Doe’ Law

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The phrases “sanctity of life” versus “quality of life” suggest two polarities in contemporary debates which have come to concern individuals, parents, hospital staff, the judiciary, the legislature and government. These debates range over many issues: abortion, suicide, euthanasia and the desperately difficult and tragic decisions which sometimes face parents and physicians in the treatment of newborns suffering from severe disabilities. In this paper I will deal with the last question only. I will not directly address the complex question of what should decide, but will consider the general criteria of decision-making. The paper has three sections. The first section will deal with some recent cases which have raised these issues in a particularly dramatic way. In the second section I will outline some recent legislation on these matters. In the third section I will seek to clarify how “quality of life” ethics and “life” or “sanctity of life” ethics approach such questions. I will conclude by defending a version of the “sanctity of life” ethic and showing how that could yield practical conclusions in the cases dealt with.

There have been many stories of this kind, but two in particular have brought these issues into the public arena. The first is that of “infant Doe.” He was born with Down’s syndrome and an impaired esophagus which prevented him from eating. The parents, acting on medical advice which seemed to have been of debatable accuracy, decided to deny medical treatment of the impairment with the result that he could not take food. He was left, unfed and untreated, in a Bloomington, Ind., hospital for eight days until he died of “natural causes” on April 16, 1982. The case went to the courts. In response to the public outcry which this event occasioned, the Reagan administration, at the President’s request, a memorandum from the Department of Health and Human Services warning hospitals that they would risk losing federal funds if they withheld from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a threatening condition, solely because of the handicap. The Administration based its position on Section 504 of the Rehabilitation Act of 1973, which prohibits any discrimination on the basis of handicap. Warning notices had to be placed and “hot lines” were established for the reporting of suspected cases. However, the regulations were challenged and a federal court declared them invalid. A final rule was eventually adopted including a number of modifications. This rule took effect in February, 1984.

By this time, however, a second story had started to unfold. Baby Jane Doe was born with spina bifida, an open spine condition; hydrocephalus, excess fluid on the brain; and microcephaly, an abnormally small head. The physicians informed her parents that, unless she had surgery to correct the spina bifida and hydrocephalus, her life expectancy ranged from a few weeks to two years. With surgery, she might survive 20 years, but would be severely retarded, epileptic, paralyzed, bedridden, and subject to constant urinary tract and bladder infections. Her parents decided to forego corrective surgery. This, they felt, would only prolong a life of suffering. They chose instead to use antibiotics to protect against infection of the spinal column.

Again the matter was taken to the courts. After a series of hearings, the case came to a U.S. Court of Appeals. In February, 1984, the court ruled: (1) that Section 504 of the Rehabilitation Act does not apply to treatment decisions involving seriously ill newborns, and (2) (in May) that the regulations themselves were “invalid, unlawful and must be set aside.” As a result of this decision the federal government was prohibited from investigating or regulating such treatment decisions. The burden of settling the controversy passed to Congress.

Finally, after more than a year of stormy debate, Congress agreed on “Baby Doe” legislation designed to protect seriously handicapped infants from the withholding of life saving treatment. The legislation...
was signed into law on October 9, 1984. This legislation requires each state to set up procedures in its child protective services system to respond to and, if proper, to intervene legally in cases where the withholding of medical treatment is disputed. The procedure would provide for consultation and notification to the state child protection agency in cases of suspected medical neglect. States which do not set up the required procedures would risk losing agency funds.

Child abuse is redefined to include the “withholding of medically indicated treatment from disabled infants with life-threatening conditions.” This phrase is defined to mean the “failure to respond to the infant’s life-threatening conditions by providing treatment (to include appropriate nutrition, hydration and medication) which, in the treating physician’s reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions.” Some exceptions are indicated where treatment is not required. These are (1) the infant is chronically and irreversibly comatose; (2) the provision of treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or (iii) would be otherwise futile in terms of the survival of the infant or (3) the provision of treatment would be virtually futile in terms of the survival of the infant, and the treatment itself under such circumstances would be inhumane.

What Would Be Implications?

What would be the implications of this legislation for Infant Doe and Baby Jane Doe? In the case of Infant Doe, the refusal of corrective surgery would seem to qualify clearly as “withholding of medically indicated treatment from disabled infants with life-threatening conditions.” Had this law been in existence in 1982, the Boomington Baby Doe could not have been starved to death because it was retarded. The situation of Baby Jane Doe seems, at least at first sight, to be somewhat different. Infant Doe was deprived of treatment which would have been given to other “normal” infants with a similar condition, allegedly because he was retarded. Was Baby Jane Doe deprived of treatment because she was, or would be, retarded? Or was it the reason the whole range of disabilities from which she would suffer even after treatment to correct the life-threatening conditions? Would treatment be required for other infants suffering from a similar range of disabilities, where the life-threatening conditions could be corrected, but the other disabilities could not? No doubt there will be further discussion aimed at clarifying the precise meaning of the law. But, as I read it, it requires that if the life-threatening condition of the disabled infant can be corrected or ameliorated, it must be treated. The exceptions provided for do not seem to apply in the case of Baby Jane Doe. She was not, apparently, irreversibly comatose, even if she would have been severely retarded. She was not “dying,” so that the treatment would not merely have prolonged dying. The treatment would not have been virtually futile in terms of her survival. Therefore, it would seem that, in terms of the law, she should have been treated.

The law does not provide the ethical rationale for its provisions and probably it should not be expected to do so. However, the ethical perspective on these matters is our major interest here. I will therefore take up that perspective, and in particular explore how “quality of life” ethics and “sanctity of life” ethics would seek to resolve the dilemmas.

We can approach the issues on three levels. The first is purely descriptive. Thus, we could begin by simply describing the functions or capacities by which we identify “human life.” These would be, for example, vital and metabolic functioning, sentience, consciousness, desire, relating to others. On a second level we could make value judgments about such functions or qualities. These functions or qualities are goods or values. On a third level we could make normative judgments about how we should respond to persons whose lives include these functions or qualities.

The crucial differences between the different ethics appear in the way in which they make these value judgments and the way in which they incorporate these value judgments into normative judgments about the right way to respond to or treat persons. For example, a “quality of life” ethic would make a value judgment such as the following: a life which has the qualities of vital and metabolic functioning, plus sentence, consciousness, desire and the capacity to relate to others, is of more value than a life which has only vital and metabolic functions. To whom are such lives of more or less value? Different types of “quality of life” ethics would reply that what counts is the value of such a life to society, to more particular groups, such as the family, or to the individual herself or himself who is living that life.

In moving to the level of normative judgments, “quality of life” ethics would then form such judgments as: such a low quality life is “not worth saving,” or “not meaningful” or “not worth living.” Thus, we are not obliged to sustain such lives, and, as some would go on to argue, may or even ought to, directly take such lives. That is, the characteristic feature of a typical “quality of life” ethic is that it rejects the principle of the equality of human lives and with that rejects the equality of human persons.

There are, however, two kinds of “quality of life” judgments evident in the stories I have recounted above. The first takes this form: infant Doe is retarded, that is, his life is of deficient quality. He fails to meet the value-test which we require individuals to meet if they are to be accepted into the community of equal persons. Therefore, we
are not called on to provide him with the treatment we would give to "normal," equal persons. This is the clearest expression of a dualist ethic, solely on the ground of handicap. Such a judgment is manifestly a form of discrimination. It violates the principle of equality and is against justice. It may well be that the decision not to treat Baby Jane Doe was based on a similar argument. But another interpretation is possible and this brings us to another kind of "quality of life" judgment.

The second type takes the following shape: the kind of life which Baby Jane would live even after the surgery would be deficient in certain qualities and would have many negative qualities such as retardation, epilepsy, paralysis, restriction of movement, constant pain or discomfort. Therefore, that kind of life would not be good or value to her. It could, indeed, be considered a harm. We ought not to harm other individuals, therefore we ought not sustain Baby Jane's life. In this kind of argument there is no direct discrimination against Baby Jane merely because her life is allegedly of less value in comparison to others. It is, of course, possible that this second kind of argument could be put forward to disguise the "real" reason for not treating which might well be of the first kind. But these arguments are genuinely distinct.

Argument Has Obvious Problem

There is one obvious problem with such an argument. As was argued in the brief presented by the Spina Bifida Association in a court case which concerned Baby Jane Doe, we cannot know what the outcome will actually be after treating such infants. In fact, many such infants have done much better than was expected. This being the case, we should be extremely cautious in attempting such judgments ahead of time. Indeed it could well be argued, that in view of the possibility of a reasonably satisfactory outcome, we should treat all such infants.

However, it may well be that tragic outcomes can be predicted with a high degree of probability. May such arguments as that presented above be used or is the approach inherently defective? Can such arguments be faulted as ethical arguments? This question has been much debated. In particular, there has been considerable controversy over one particular form of the argument. This has proposed that, when the infant's condition is such that it has no potential for human relationships, or if the potential would be utterly submerged and undeveloped in the mere struggle to survive, then that life has achieved its potential and thus has no further claims on our life-sustaining care. As I have already noted, this kind of argument does not seem to be of the discriminatory kind which evaluates some living individuals as less than others, and so denies fundamental equality. In this account, such infants have less or no further claims on our care because a certain kind of living is no longer a good or value for such infants. The issue is the good of this individual, not a comparison by which this individual is judged less good or valuable than other individuals. The basic problem seems to be in the way the value judgment is made about that kind of living. Thus, a certain level of living is judged to be a good or value for this individual only if it can (i.e., has the potential) to provide for other "higher goods" such as human relationships. Some critics would see here a subtle form of a "consequentialist" ethic. I suggest there is another difficulty. The capacity inherent in one level of living to make possible "higher" levels of living is one aspect of the goodness or value of that level of living. But it is not clear to me, that when that capacity is lacking, this limited living ceases to be a good altogether for the individual who lives that life. It is still the living of a person, and that living person still has claims on our care. A better approach would be not to attach degrees of good to the living of that person, but to recognize that we have positive duties in response to that living person and then to examine the scope and limits of those duties. This view of the matter is characteristic of the typical "sanctity of life" ethic and I will now seek to outline the basic form of this approach.

In the Roman Catholic tradition, there are two especially significant statements of special relevance to the subject of this paper. The first is from Pius XII:

...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 more important good too difficult. Life, health, all temporal activities are subordinated to spiritual ends. On the other hand, one is not forbidden to take more than strictly necessary steps to preserve life and health, as long as one does not fail in some more serious duty. There are several noteworthy features of this statement. The question is whether the means of treatment impose a grave burden on the subject or another. The dominant perspective is that of the subject-person who bears responsibilities in relation to the spiritual ends of human living. A requirement to bear what is, for this person, too great a burden in relation to her or his capacities, would place such a weight on her/him that it could exceed her/his moral strength, and thus make the attaining of these spiritual ends excessively difficult. Thus, the duty to sustain one's life is a positive, but a limited duty. Further, in this matter the limits are expressed by saying that one is obliged to use only "ordinary means" to preserve that life. Ordinary means were usually understood to be those which held out a prospect of benefit, alleviation or cure, and did not entail an undue burden in terms of pain, anxiety, expense, etc.
The second relevant statement is the Declaration on Human Beings issued by the Sacred Congregation for the Doctrine of the Faith in 1980. This document explains the reasons why human life is good to be fostered and protected.20 1) Human life is the basis of all human goods, and the necessary source and condition of every human activity and of all society. 2) Human life is sacred, and no one may oppose it at will. 3) Believers are in life something greater, namely, a gift of God's love, which they are called upon to preserve and make fruitful.

The same document indicates, in a summary way, why the taking of the life of an innocent person is wrong: a) It opposes God's love for that person; b) It violates a fundamental right; c) It is a rejection of God's sovereignty.

The document then deals with the obligation to preserve one's own life. It notes that the traditional terms "ordinary" and "extraordinary" may seem today to be less clear. The terms are imprecise and modern medical science has made rapid progress in developing new treatments. Some, it is noted, prefer to speak of "proportionate" and "disproportionate" means. According to the statement, the correct judgment can be made in regard to the means by studying: 1) the type of treatment; 2) its degree of complexity and risk; 3) its cost; 4) the possibilities of using the means; 5) comparing these with the results which can be expected; 6) taking into account the state of the sick person and his or her physical and moral resources. It may thus be judged that the treatments impose on the patient strain and suffering out of proportion to the benefits to be gained.

The particular difficulty which arises in our present context is the application of these criteria in the case of an infant. The latter document calls on us to take into account the "moral resources" of the person. As Pius XII made clear this factor is crucial to the question since the key question is whether the subject may or may not be diverted from the "spiritual ends" of human moral living by too burdensome obligation. In the case of an infant, of course, we do not have a person capable of moral choice, that is, we do not have a moral subject. The infant cannot itself make the kind of balancing judgment between burden and benefit needed in resolving the question as to whether the treatment is or is not, proportionate to the results to be expected. Therefore, in some way or other, others must make that judgment.

As I have argued earlier, there are some ways of making that judgment which must be rejected. The discriminatory kind of "quality of life" judgment is unacceptable. The second kind of "quality of life" judgment, which seeks to determine whether or not a certain kind of life is, or is not, a good for the infant, seems to be less than fully satisfactory. There is another way, typically followed by those who would uphold a "sanctity of life" ethic.

The starting point of this approach is to recognize that the week and defenseless are to be cherished and protected as our neighbors in greatest need.21 We have, then, a positive duty to protect that infant capably, means protecting its life. But, like all positive duties, this may be limited. These limits are set by the inherent limitations on the means of treatment available, considered in respect to the limitations arising from the disabled condition of the infant. When there are insurmountable limits as to what we can do for this patient, there are limits to what we ought to do. Thus, the following criteria seem to be acceptable. Treatments, in view of the disproportion between the benefits they may confer and the burdens they will impose, are themselves "extraordinary," or disproportionate to the moral goal of care for the infant when:

1) treatment may be life-sustaining, but causes further disabilities (for example, some added impairment);
2) treatment may be life-sustaining, but is inseparably associated with unduly burdensome conditions (for example, pain or risk);
3) treatment is not life-sustaining at all, but only prolongs dying.

However, there are other factors which must be considered. Some writers who would not doubt wish to uphold a "sanctity of life" rather than a "quality of life" ethic, point out that "the obligation to provide means necessary to preserve life cannot be reduced to the distinction between ordinary and extraordinary means. It is determined by the interests of the patient, her/his relationship with the provider and the ability of the latter to relieve the patient's need without serious hardship."24 Furthermore, just as the principle of limitation or positive duty can be applied to the duty of a person to sustain her/his own life, so it can be applied to the duties of others to sustain the life of another. The positive duty to sustain the life of another does not bind at all cost, in the sense of requiring unlimited sacrifice on the part of the one seeking to sustain that life. How then are the limits on this duty to be determined?

Father Ashley's Proposal

Another author, Benedict Ashley, O.P., has proposed the following: (1) Are the expenditures proportionate to the benefit the patient will receive? (2) What would be the "reasonable interests" of the patient, who would hardly wish her/his family to be unduly burdened, (3) The resources of the family should be shared by all and not exhausted on a single member.25 The first point is interesting in that it adds a further point of reference to the basic question of the proportion of burden/benefit to the patient. Now it is asked whether the burden on others (the family) is proportionate to the benefit to the patient. The second point shifts from the usual expression "best interests" of the patient,
to "reasonable interests," which thus allows the burden to be taken into account in terms of what the patient would be presumed to wish for that family. The third point involves a principle of fairness, which governs the distribution of resources within the family. Thus, parents would not be unfair in limiting the resources expended on one member of the family, where such expenditure would be to the detriment of the others. All of these questions would, no doubt, be very difficult to answer in a practical situation. But they seem reasonable in principle. They indicate, furthermore, that there are more questions to be asked than whether the available treatment can correct or ameliorate the life-threatening condition. We may ask the limits on the duty to care which derive from the means of treatment (whether they are "ordinary" or "extraordinary" or "proportionate"): (2) the condition of the patient (whether that condition is irremediable or remediable only to a limited degree); (3) the resources — physical, psychological, financial — of the persons who bear responsibility for the patient; (4) the resources of society, in the sense that these are not infinite and hence, must be allotted according to some principle of distribution.

All these factors set limits. But the question still remains as to the criteria of relevance and relative importance within which these factors ought to be assessed. The perspective from which these criteria ought be constructed is that of the patient-person.26 Another approach would be exposed to the danger of imposing the expectations and values of others — in this case adults — on the infant. But having proposed this, we still have to discern how that patient-centered perspective should be interpreted. Should we construct this perspective according to an image of the patient-person as merely a calculator of maximum benefit to self, or is it more appropriate to proceed with an image of that patient-person as a moral agent, better, as if that patient-person were a moral agent? If we select the first option, we would encounter serious difficulties. How are we to know, for example, what calculation of burden/benefit would count for such a patient as a net gain? It may well be that a very limited form of life would be conceived as a benefit, at least when compared with non-existence. On the other hand, if we were to construct an image of this patient-person as an agent capable of moral choices, we could construe in some way what such a moral agent would reasonably want. For example, such a moral agent would reasonably not want to impose an impossible burden on the family, nor would such an agent choose to take a course of action which would expose the agent herself or himself to a condition of life which, after reaching a stage of development where some degree of consciousness and freedom made a striving for moral and spiritual self-realization possible, rendered the attaining of the higher spiritual good too difficult. Similarly, such a moral agent would not demand that resources be distributed in such a way as to favor that agent at the cost of unfair deprivation of resources from other moral agents.

The obvious objection to such a construction is that the infants who are being considered here are not moral agents.27 That being the case, such a construction inevitably involves an imposition of our values on those infants. The image of a moral agent which we form is inevitably an image of ourselves. It has to be admitted, of course, that any such attempt is a construction. Nevertheless, such a procedure would preclude some more objectional moves. Thus, for example, we would be prevented from imposing on that patient an arbitrary judgment that she/he was not a person like us, or was a person, but of less inherent value than us. Similarly, we would be precluded from any judgment that such a patient has lesser claims to care than we would have. Furthermore, we would be precluded from speculations as to whether such a patient had less potential than we have, and for that reason had lesser claims to care.

But we could include a consideration of whether a life lived under conditions of severe pain and debility would make the pursuit of moral ends too difficult. Thus, we would have to ask ourselves whether treating a life-threatening condition and so prolonging life, when we cannot correct or ameliorate a condition which would produce severe suffering, would place that patient in a position requiring moral effort beyond reasonable limits. If we would not want to be placed in such a situation calling for moral heroism, then we ought not place another in such a position.

A Compelling Perspective

Such a perspective compels us to recognize a fundamental equality, not only an equality of life, but an equality of persons. Precisely insofar as we construct the judgments of the patient according to what we value, we recognize that other as an equal. However, a further limit must be held clearly in view. There is a difference between constructing such a judgment according to the values we hold, and constructing a judgment on the basis of our situation-dependent expectations. Thus, on the basis of what we have experienced of life and its possibilities we might judge a very restricted form of life to fall far short of our expectations. But we are not justified in concluding from this that such a diminished form of life must be not meaningful for another, and so not valuable for another. For an infant who has not had our experience of life, a diminished form of life may indeed be valuable, and certainly more valuable than no life at all.

Any kind of judgment about the life of another which attributes degrees of value to that life on the basis of quality criteria drawn from our expectations of life is inherently defective. Such judgments are an
imposition of our presuppositions on another. As such they fail precisely because they set aside the equal personhood of the other. On the other hand, if we recognize the other as an equal person, we may reasonably anticipate that, when that other reaches a level of development where some, at least minimal, level of freedom and moral standing becomes possible, there are levels of suffering which could make that striving too difficult. We are then not engaged in deciding for another whether or not her/his life is more or less valuable as another, we acknowledge in that other a common humanity with a common capacity for moral fulfillment. At the same time, we recognize certain limitations, such that where the call to moral fulfillment reaches an individual in a condition of considerable pain and suffering, the following of that call may be simply beyond that individual’s moral capacity. Thus the question to be asked is this: if we correct this individual’s life-threatening condition so that she/he survives, but cannot correct conditions which will leave that individual in pain and suffering, what will be the human condition of that person when she/he regains a stage of free, moral agency? If it can be anticipated with a high degree of probability that the condition will be such as to impose a burden beyond reasonable bounds of human moral strength, then we may judge that our obligation to provide care has reached its limits.

In the light of these considerations, we can consider a further limit to be added to those proposed above. Warren T. Reich has proposed that a limit to the obligation to treat is set “when excessively burdensome qualities are perpetuated by life-sustaining treatment.” He explains this in detail as follows:

As regards those infants who can be expected to experience at least a minimal self-consciousness and freedom of will and who therefore will be striving to achieve moral (or moral-religious) self-realization, the duty to preserve life may be limited by the excessive hardship that would foreseeably be experienced by the patient if his entire striving toward a moral meaning in life were to be totally submerged in or utterly strained by the mere effort to survive and by the suffering that accompanies that effort. This would seem to me to be acceptable with certain provisos, such as that a life is less valuable in itself, or to others, or to the infant, if certain qualities such as “potential” or “capacity for human relationships”; (3) provided that the judgment focuses on the equal personhood of the infant and thus construes the significance of the burden precisely as rendering the pursuit of moral (and religious) self-realization too difficult for a person considered as sharing our common, limited human strength.

Reich suggests that this could apply to infants afflicted with meconium ileus, ingyomyelocele. Thus, it might well apply to Baby Jane Doe, if the very pessimistic prognosis were correct. But, as I have indicated there are reasons for doubting the reliability of such prognoses, both in this particular case and in the generality of such cases. While such doubt persists, the presumption should be in favor of treatment. However, it would seem to be possible that there could be other kinds of cases where such a pessimistic prognosis could be made by reasonable medical judgment with a high degree of probability. In such a case, the range of complex ethical questions which have been discussed here, could legitimately be asked. While subsequent discussion will no doubt further clarify the precise meaning of the new law, it must be asked whether, taken literately, the requirements allow sufficient scope for such legitimate concerns.

REFERENCES


7. FL 98-45 (98 STAT. 1752), 42 USC 5102.

8. There is a difference in approach between that of the rules issued by the Administration and that of the new law. The former sought to extend the notion of discrimination to cover cases of withholding treatment. The latter follows a different route; it defines child abuse to include such cases.


Knowledge: Is It Ever Forbidden Fruit?

Arthur J. Dyck

We are so accustomed to thinking of knowledge, and the gathering of it, as unqualifiedly good, that even faithful Christians and Jews are prone to forget that their scriptures depict the quest for knowledge as a source of tragic separation from God. For Christians, the human choice for the unqualified pursuit of knowledge is what required God's repair of creation through the saving power of Christ.

The reminder of our tragic relation to the quest to know everything is graphically portrayed in the second and third chapters of Genesis. Here is the account of the creation of man and woman and of a wonderful garden. Of its lovely fruit they may freely eat, but not of one tree — the tree of the knowledge of good and evil. To eat of that tree means death. But Adam and Eve, beguiled by the charming serpent, did eat of it and the results are with us still. Our earthly life is not a perfect paradise without pain and sweat. Above all, they and we are separated from the tree of life and are mortal, not able on our own power to live eternally.

But is knowledge really to be regarded as forbidden fruit? How can a good such as knowledge be so regarded? Is knowledge, often seen as a good in itself, ever to be seen as evil in itself, and the desire for it, no less evil?

What has prompted me to dare consider any knowledge, that sacred fruit of scholars' treasured labors, as, in any sense, to be forbidden? What fool would attack a growth industry like research? Government spending for medical research alone soared from 18 million dollars in 1940, to 240 million dollars in 1950, and from there to more than three billion dollars in 1979. The lure of forbidden fruit is rather strong as even Eden's owner and manager soon discovered. Nevertheless, on the assumption that David really beat Goliath, I will fashion

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