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The President's Commission for the Study of Ethical Problems in Medicine: Its View of the Right to Life

Arthur J. Dyck

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The Commission, to be discussed in this essay, has been much cited in the medical literature and the media. Most of the comments have been laudatory. That concerns me, because I believe that its report of March, 1983 takes a less than satisfactory view of the right to life. The report I have in mind is entitled "Deciding to Forego Life-Sustaining Treatment." I should add that the Commission's full name is the "President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research." (For convenience, I refer simply to the "Commission" and all subsequent page references refer to the one report named above.)

The Commission considers three values to be "dominant values." These are self-determination, well-being, and equity. As we shall see, however, equity does not actually guide the nature of medical care given to patients; it applies to equal access to health care. Since life is not singled out as a dominant value, the question arises for me as to what status our right to life has for this Commission in this report. The Commission deals with a number of medical situations but I wish to focus on their discussion of care for seriously ill infants where conceptions, both of the right to life and the right to self-determination, are explicitly involved under circumstances of great ambiguity where, as some like to say, everything looks grey. To put our question in its bluntest form: Does the Commission sometimes favor infanticide in the context of caring for seriously ill infants?

If by infanticide we mean directly killing, with measures known to be lethal, newborns or very young children classified as infants, the Commission should be viewed as totally opposed to infanticide for the following reasons:

- 1) "A physician's shooting or poisoning of a dying patient, even at the patient's request and from merciful motives falls within the definition of murder" (p. 33).
- 2) The omission of life-saving is to be regarded in the same way, as murder, if the result is the same (p. 34).
- 3) "Society seems well served by retaining the prohibition on killing" (p. 36).
- 4) The traditional prohibition of the Hippocratic Oath is to be retained: "Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course" (p. 79). The reasons for following the Oath in this respect is that to do otherwise would risk: loss of patient trust; damage to a professional's self-image; and undermining of wholehearted treatment of gravely ill patients. (There is no mention here of violating a right to life and we will see why momentarily.)
- 5) Physicians are to favor life (p. 207).
- 6) Early intervention for infants, seriously ill, is cost/effective (p. 206).

The Commission has apparently rejected infanticide for physicians and other health care providers. They also reject acts of omission that result in death as akin to murder. However, this does not end the matter. They suggest policies which have heretofore resulted in the deaths of *handicapped* infants by omitting life-saving intervention, including instances where the intervention would be considered routine for non-handicapped infants. By the Commission's own reasoning, these should be reckoned as cases of infanticide and murder. Let us carefully trace the Commission's position on this.

First of all, recall that life is not a basic or "dominant" value for the Commission; self-determination, well-being and equity are. The Commission explicitly lists the "right to life" as among the phrases that constitute "empty rhetoric" and that "have been used in such conflicting ways that their meanings, if they ever were clear, have become hopelessly blurred" (p. 24). No affirmation here of the idea that persons are endowed with an inalienable right to life! The Commission believes that self-determination and well-being are the values that create obligations and are the basis of rights.

One very pertinent example illustrating this point occurs in the context of the Commission's commentary on the commitment of acute care hospitals to the extension of life. This commitment is, the Commission maintains, an important source of trust and an endorsement of the value of persons, both medical necessities. Nevertheless,

the Commission admonishes these hospitals by asserting that patients should not face such marked resistance to a decision to forego life-sustaining treatment as to either rob them of the right to self-determination or damage their mental, or physical health" (p. 108). The Commission is not limiting its remarks to patients who are terminally ill!

For newborns, the Commission generally favors parents, where available, as surrogate decision-makers. The decisions of surrogates should be guided by two principles: respect for self-determination; and the welfare or well-being of the patient in question. Equity or equality is not invoked at this point. The apparent reason is that it does not apply to decisions regarding care, only to decisions regarding access to care as noted earlier. For infants, only the principle of well-being applies. I remind the reader that the infants we are talking about are *seriously ill*; only some of them may be correctly, though with difficulty, judged to be *terminally ill*; some of them may be treated with the prospect of a normal life-span, or in the case of certain handicaps, a life-span typical of that handicap. Where then, in the case of handicapped infants, is their right to live, and where is their right to equal treatment, that is, their life to have the same life-sustaining treatment afforded normal infants with similar ailments, such as a bowel obstruction? Perhaps these are implicitly recognized by the Commission though not mentioned. Perhaps they are not regarded as rights. The answers to these questions require a further probe into the exact advice the Commission gives to surrogate decision-makers.

Commission Says Surrogate Should Decide

The surrogate should, in the judgment of the Commission, decide whether the continued existence of the seriously ill infant would or would not be "a net benefit to the infant." This, for the sake of the self-determination that the infant lacks, should be done from the infant's perspective. In the Commission's words, "The Commission is concerned with the value of the patient's life for the patient" (p. 135). It is this value to which the Commission refers when it speaks of judging what is for the patient's well-being or best interests. The Commission, however, is concerned at the same time that enormous resources may be spent, for little benefit, to sustain "a painful and burdened life for an individual who has little or no capacity to enjoy it." How much is a little in benefit, or a little in capacity? Aware that many do not think it beneficial to sustain the infants with Down's Syndrome, the Commission categorically suggests that the lives of persons with this degree and range of mental handicaps should be saved, when possible, because their lives are generally meaningful.

From the standpoint of equality then, lives are not seen as equally

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worthwhile, and some lives are not worth sustaining. From the standpoint of the value of life, its worth depends upon the worth assigned it by the patient or, in the case of infants, whether handicapped or not, by what is thought to be the worth that would or should be given it. An individual's life is a right only insofar as it is claimed as such, or when it cannot be claimed by that individual, life is a right insofar as it is judged, by someone else, to have sufficient worth for that individual.

But if physicians and health professionals are to favor life, and hospitals are committed to extending it, would not there still in fact be a functioning right to life, even for handicapped infants? There are two aspects to care for handicapped infants that militate against this.

First, the Commission recommends that parents generally be the surrogates for their own infants whenever possible. The Commission is fully aware of the well-publicized data on parental choices not to treat their seriously ill newborns, even in instances where their lives can clearly be sustained and their illnesses are not terminal. These instances included failure to save the lives of infants with Down's Syndrome whose lives, the Commission thinks, should be saved. The Baby Doe case in Bloomington, Indiana, is only one case in addition to the many reported in medical journals. The Baby Doe case is especially notable because it was a state supreme court that sanctioned a parental decision not to feed and not to operate on their infant child. By the Commission's own standards, not feeding an infant would qualify as murder, as a failure to act that leads to death.

The Commission depicts the relation between parents and physicians, with regard to treating seriously ill newborns, in the chart below.

Physician's Assessment of Treatment Options	Parents Prefer to Accept Treatment	Parents Prefer to Forego Treatment
Clearly beneficial	Provide treatment	Provide treatment during review process
Ambiguous or uncertain	Provide treatment	Forego treatment
Futile	Provide treatment unless provider declines to do so	Forego treatment

(Table 1, p. 218)

From this chart we can see that the physician only strives with the parents when parents refuse clearly beneficial treatment, or in the case of futile treatment, when parents want treatment that the provider is

unwilling to offer. If life were a dominant value, one would expect that ambiguous or uncertain cases would be decided on the basis of maintaining life. Such is not the recommendation of the Commission, and this certainly qualifies what they say about physicians favoring life.

Not just parental attitudes but also those of physicians affect the care seriously ill infants will receive, and physicians influence parents by their assessments of how beneficial treatment will be. They tend to see treatment for mentally handicapped infants as futile. The Commission is willing to see infants with Down's Syndrome treated; these are infants who are usually moderately retarded. But many physicians take issue with this, and the decisions of parents will be based on their assessments. Physicians often use the term "hopeless," for example, to describe both a condition of terminal illness, and one of a permanent mental handicap. As many as sixty-one percent of the physicians surveyed in California in 1975 would, with parental consent, fail to provide life-saving treatment for a Down's Syndrome infant. In a national survey, eighty-five percent of the pediatric surgeons, in 1977, said they would acquiesce in parental wishes not to treat an infant with Down's who also had congenital heart disease; sixty-five percent of the pediatricians would do likewise. Another study found that fifty-one percent of the pediatricians surveyed in Massachusetts would not recommend surgery for a Down's Syndrome infant with intestinal blockage. The Commission cites these three studies (p. 208). Hence, the Commission is aware that what by their own formulations could be deemed murder or infanticide, will take place, unless some protection, not now in place, is provided and enforced. The Commission explicitly rejects legal and governmental interference in these decisions: Self-determination both of health professionals and of patients or their surrogates is a right not to be interfered with.

One might well ask how the value of life can be subordinate to the value of self-determination. The value of life is to be judged by the individual, and when it is judged by another person, it is done on the basis of the well-being of that life, particularly whether that life will still allow the individual to be at least somewhat self-determining. Self-determination, for the Commission, consists in "a person forming, revising, over time, and pursuing his or her own particular plan of life" (p. 43).

During the time the Commission was preparing the final draft of its report, I had the opportunity to read and comment on a draft that closely resembled the final one — the one I have been describing. I noticed and commented in a letter that "life" was not treated as a dominant value. In reply, Dr. Joanne Lynn wrote a cordial letter in which she said, on this point, that "the report does not list life as a 'dominant value' because, for the purposes of this report, the value of life is included in the other categories, especially well-being and self-

determination" (Nov. 1, 1982). The Commission also saw fit not to change their minds, or their report, in this respect.

Now, regardless of how the reader may think or feel about the Commission's conception of rights, it should be evident that it is not making a separate right out of the right to life. Self-determination is what others are obligated to secure and protect. There is no unqualified right to life: Its value is to be determined by each individual; and for individuals deemed incapable of judging the value of their own lives, what value life has is based on someone else's assessment of their best interests or well-being. Of course, we are talking about the value of an individual's life in the context of health care decisions. This is a sphere of individual liberty for the Commission. The Commission is not willing simply to assert or accept what the American Declaration of Independence designates as an inalienable right to life. Unlike that Declaration, the Commission views every judgment of the value of individual life as either a self-assessment of its utility, or as an assessment of its utility by someone else. While the value of life may not always have a high degree of utility, self-determination for the Commission always does. Indeed, any loss in one's capacity to be self-determining is deemed a loss in the utility of one's life to oneself and to others. For the Commission, then, there is no strictly equal right to life and no stable, high value to be placed on life. Entitlement to equality of one's basic right to life is, therefore, always qualified by the differences in utility, whether judged by oneself or by someone else. And the degree of that utility is largely, sometimes exclusively, a function of the degree to which someone is self-determining. The effect of this kind of thinking is that it sanctions discrimination and infanticide relative to handicapped infants, in principle and in practice.

It is no wonder then, that Congressional action was necessary and that it came on October 9, 1984 (H.R. 1904) in the form of amendments to the Child Abuse Act. Congress moved against any discriminatory treatment of seriously ill handicapped infants: Infants with disabilities are to receive the same care expected for infants generally. That specifically includes appropriate nutrition, hydration, and medication. But health professionals, and all of us together in the larger community, will need to be alert if this law is to be effective. As we have seen from the Commission's report, there are many physicians who will be reluctant to give optimistic prognoses when infants have disabilities, in fact or in prospect, and parents and others may have difficulty discerning what the real prospects are. And, I need not add, prognoses for infants are often so uncertain. So, despite the help from current law, the struggle will continue for straight thinking about what justice (equality of basic rights) demands, and for the willingness to meet those demands. It is a struggle for the very lives of infants everywhere.