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# The AMA's Equivocal Quality of Life Guideline Justifies the Baby Doe Rules

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## I. Introduction

Although the American Medical Association spent years drafting its recent guideline for treatment of severely handicapped newborns, the issue is once again in the news. Now the federal government has intervened in the matter with its Baby Doe regulations which require doctors to give handicapped newborns all possible life-sustaining treatment, unless imminent death is considered inevitable or the risks of treatment are prohibitive.

The Sept. 15, 1983, issue of the *New England Journal of Medicine* strenuously objects to these proposed Baby Doe regulations, charging that "For the the government to think that it can do better with a set of general rules, which are of necessity insensitive and vague when applied to particular patients is both arrogant and foolish."<sup>1</sup>

This may be so, but as this article will show, the medical profession's own guideline on this matter is itself so equivocal that the *New England Journal of Medicine* charge is really just a case of the pot calling the kettle black. Physicians, abiding by this guideline, in good faith, often can reach contradictory conclusions about whether treatment is ethically required, even in instances where failure to treat means the patient will die.

If, as I think the following pages show, my claim is true, then it is surely no wonder that the federal government has stepped in to afford some guidance (however inadequate) to a profession which in this matter of life and death, has failed to provide sure guidance for itself.

## II. The Current AMA Guideline on the Treatment of Handicapped Newborns

The current AMA guideline governing the treatment of defective (but *not* terminally ill) newborns is found in the AMA Judicial Council's publication, *Current Opinions . . . 1984*.

Section 2.14 (entitled "Quality of Life") runs to nearly 150 words, divided into two paragraphs. Nonetheless, as my analysis will soon show, this wordy guideline does not really offer physicians much useful direction.

In fact, the second paragraph of the guideline offers no standards at all by which to judge *whether or how energetically* to treat defective or severely deteriorated patients. It merely states that, except in rare instances, parents, rather than physicians, must make the ultimate judgment about whether to exert maximal efforts to sustain the lives of their desperately ill newborns.

Thus, the substance of the AMA's current quality of life guideline remains to be found in its first paragraph, which reads as follows:

- (1) In the making of decisions for the treatment of seriously deformed newborns or persons who are severely deteriorated victims of injury, illness or advanced age, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society.
- (2) Quality of life is a factor to be considered in determining what is best for the individual.
- (3) Life should be cherished despite disabilities and handicaps, except when the prolongation would be inhumane and unconscionable.
- (4) Under these circumstances, withholding or removing life supporting means is ethical provided that the normal care given an individual who is ill is not discontinued (*numbers added*).<sup>2</sup>

The test of a guideline is the guidance it gives. If you are a physician who regularly deals with handicapped or deformed newborns, you probably already know how little help this AMA guideline gives. If you are not such a physician, imagine for a moment that you are, and that you have turned to this guideline for help in a difficult situation.

What standards does it recommend that you use in deciding whether and how aggressively to treat your nonterminally ill but seriously defective newborns and other severely deteriorated patients?

Line 1 rightly directs you to think first of "what is best for the individual patient," but it does not yet tell you *how* to determine "what is best": massive treatment, minimal treatment, or no treatment at all.

And although line 3 of this quality of life guideline rightly cautions you to cherish life "despite disabilities and handicaps, except when the prolongation would be inhumane and unconscionable," it does not offer you any standard by which to judge *when* prolongation of life is "inhumane and unconscionable" — which is the very information you are seeking from the guideline.

Not even line 4 helps. It begins with the phrase "Under these cir-

cumstances . . .," falsely assuming that with the help of the previous three lines, you have been able to identify the circumstances in which prolongation of life is "inhumane and unconscionable."

It ends by cautioning you that, in such circumstances, "withholding or removing life supporting means is ethical provided that the normal care given an individual who is ill is not discontinued."

This sounds good, but, in fact, it fails to answer the crucial and very controversial questions about such patients which it is intended to answer: What constitutes *normal* care in the abnormal circumstances surrounding seriously deformed newborns or persons who are severely deteriorated victims of injury, illness or advanced age? What constitutes *normal* care for patients whose illness is not fatal, but whose quality of life is radically lower than that of the average human being? The AMA quality of life guideline does not say.

Were Section 2.14 merely a guideline which fails to guide, one might lightly dismiss it as another noble, but somewhat amateurish attempt to solve a very difficult problem. For a number of reasons, however, the current AMA guideline is far more than an instance of words which have missed their mark.

First, despite its lightweight character, it is the most authoritative currently-accepted standard of the world's largest and most prestigious medical association — a standard on which thousands of physicians rely. This fact alone magnifies the gravity of its failure to offer clear guidance.

But more importantly, as will be seen, a flaw in this guideline makes it a deadly threat to many innocent human lives. Embedded in it is one seemingly straightforward statement (line 2), which can and will be relied on as a standard: "Quality of life is a factor to be considered in determining what is best for the individual."

Indeed, this line constitutes the substantive heart of the AMA guideline, for despite the guideline's length, "quality of life" is the *only* factor it proposes as being relevant in determining what is "best for the individual" who is defective or who is seriously deteriorated because of disease or injury. As a result, in the minds of physicians who rely seriously on this AMA guideline, judgments about their patients' quality of life will play a large role in determining the treatment afforded to those patients.

This would not be a problem if this line of the AMA's quality of life guideline offered physicians an unambiguous standard to use. Unfortunately, it does not.

## III. Two Ways of Employing This Guideline

Note that though this AMA guideline says that "quality of life is a factor to be considered," it fails to indicate precisely *how* it is "to be considered." As will be seen, this failure poses serious problems for those who rely on the guideline, for, in many cases, the decision about

whether treatment is ethically necessary hinges not simply on consideration of quality of life as a factor, but rather on the way in which quality of life is considered.

Physicians can consider quality of life in two essentially different ways: 1) simply in itself, as the condition or quality of life of the patient, regardless of how that condition comes about, or 2) in terms of the effect which treatment will have on the patient's condition or quality of life.

The difference between these two ways of considering a patient's quality of life may seem to have little practical significance. But the following examples show, reliance on one as opposed to the other can mean the difference between life and death for a number of patients, particularly for those who are severely handicapped. A discussion of each way of considering quality of life follows.

#### A. "Quality of Life" Considered Simply as "The Condition or Quality of Life of the Patient"

As was indicated above, "quality of life" may be considered simply as the condition or quality of life of the patient, regardless of how it comes about. To consider quality of life in this way, we need to know only the patient's current or likely condition: retarded, comatose, maimed, paralyzed, and so forth. Whether drugs, drink, genetic defects, an accident, or medical treatment caused this condition is irrelevant. An example will show the consequences of "considering quality of life" in this way.

##### 1. Mr. White with a Brain Tumor

Suffering from a brain tumor, wealthy Mr. White can save his life only by having the tumor surgically removed. But the relatively painless excision of the tumor will gravely retard him. As a result, he will lose his job as president of a large manufacturing company and will no longer be able to care for himself or for his family. On the contrary, he will himself require constant care by others.

If "quality of life" is taken simply to indicate "the condition or quality of life of the patient, regardless of how it comes about," then following the AMA guideline, one could legitimately conclude the following: grave retardation constitutes a very poor quality of life (line 2); surgical reduction of Mr. White to such a retarded state would be "inhumane and unconscionable" (line 3); and therefore it would not constitute "normal care" (line 4). Obviously, one can conclude from this that such surgical treatment of Mr. White's brain tumor is optional and may legitimately be refused by him.

##### 2. Retarded Mr. White with Pneumonia

Let us suppose, however, that Mr. White decides that life at any level is preferable to death. His doctors successfully remove the brain tumor and his life is saved. A number of months later, our now gravely-retarded Mr. White contracts simple pneumonia which can be quickly cured with antibiotics, but which, if not treated, will take his life.

Again the question arises: to treat or not to treat?

If "quality of life" is still taken to indicate simply "the condition or quality of life of the patient, regardless of how it comes about," then those charged with making the ethical decision do not now face a situation essentially different from that which led them earlier to judge that life-saving removal of the brain tumor was ethically optional.

Since Mr. White's mental condition (or quality of life) has not risen above that which was earlier judged to be so poor that life-saving excision of the tumor was ethically optional, life-saving treatment of Mr. White's pneumonia must also be ethically optional. Specifically, for retarded Mr. White, when "quality of life" is considered in this way, one is not required to perform the relatively easy and inexpensive life-saving act of administering penicillin.

(Nor will the other criteria in the guideline reverse this decision. For if physicians had earlier judged that *reducing* Mr. White to such a low quality of life was "inhumane and unconscionable" (line 3) and certainly not "normal care" (line 4), the guideline itself now offers them no new reason to change that judgment when they must decide whether to *maintain* Mr. White in such a reduced condition.)

This does not mean that retarded Mr. White's physicians are ethically forbidden to administer penicillin to keep him alive — only that, according to this understanding of "quality of life," they could legitimately omit it. Most doctors in this situation would save Mr. White. But that sociological fact is irrelevant to our consideration of the meaning and usefulness of the current AMA guideline, which says only that "quality of life is a factor to be considered in determining what is best for the individual." The above examples show that if "quality of life" is considered simply as "the condition or quality of life of the patient, regardless of how it comes about," then treatment may be judged ethically optional for patients whose quality of life falls (or is likely to fall) as low as that of Mr. White. This is a legitimate understanding of the current AMA guideline governing treatment of handicapped newborns.

It is precisely this understanding of the "quality of life" guideline which concerns the Reagan administration in its Baby Doe regulations: the letting of children die not because of the extreme cost

of treating them (in terms of time, money, and suffering), but simply because they are physically or mentally handicapped.

#### B. "Quality of Life" Considered in Terms of "The Effect Which Treatment Will Have on the Patient's Condition or Quality of Life"

In a number of cases, a second way of employing "quality of life" as a factor to be considered in determining what is best for the individual will lead to treatment being judged ethically mandatory which would be judged optional if the first understanding of the guideline were employed.

This second way also considers quality of life as a factor, but not simply as "the condition or quality of life of the patient, regardless of how it comes about." Rather, it considers quality of life in terms of the effect treatment will have on the patient's quality of life.

Although this second way employs quality of life somewhat differently from the first, it remains nonetheless a quality of life standard, for its use requires many direct judgments of quality of life, e.g., of the relative goodness or badness of various mental and physical conditions. Specifically, it relies on its evaluation of effects as themselves good or bad as a criterion for judging otherwise neutral means to achieve those effects.

Astute readers may realize by now that this second way of considering quality of life (in evaluating what is best for patients) is really nothing other than the traditional ordinary/extraordinary means standard.

Although many of its defenders might deny it, in many respects this traditional standard is actually a quality of life standard. It considers a patient's quality of life by weighing goods such as life, health, and intelligence against evils such as the great monetary expense, pain, and physical or mental debility which arise from the use of the means to preserve those goods. In Mr. White's case, it would judge life itself to be a good and the retardation arising from his life-saving treatment to be bad.

In this way, the ordinary/extraordinary means standard does precisely what the AMA guideline calls for, employing "quality of life . . . (as) a factor to be considered in determining what is best for the individual."

Yet, because its way of considering quality of life as a factor differs from the way in which it was considered in our earlier analysis of Mr. White's conditions, the ordinary/extraordinary means standard reaches a different judgment about the obligation to treat his pneumonia.

Recall that taking "quality of life" to indicate simply "the condition or quality of life of the patient, regardless of how it comes about" leads to the conclusion that for Mr. White, both the life-saving brain surgery as well as the life-saving penicillin are ethically optional.

If one now considers these treatments in terms of their effects on Mr. White's quality of life, the judgment regarding his life-saving brain surgery remains the same. Because the life-saving operation will itself cause such grave retardation as well as loss of the many goods which depend on normal intelligence, the operation is, in this circumstance, extraordinary and need not be performed.

But the later use of penicillin to treat retarded Mr. White's pneumonia has no significant detrimental effect on his quality of life. It neither increases nor diminishes his retardation. Therefore, since the means to save his life (penicillin) does not have an adverse effect on Mr. White's quality of life (indeed, it preserves his life), then considering quality of life in this way (which is certainly in conformity with the AMA guideline) leads to the conclusion that Mr. White's physicians must treat his pneumonia — a conclusion directly contradictory to that reached by considering "quality of life" simply as "the condition of the patient, regardless of how it came about."

In this case, and in the case of most severely handicapped newborns, considering "quality of life" in one way as opposed to the other makes a fatal difference. It literally means the difference between life and death.

#### IV. Failure of the AMA Guideline

How, then, should "quality of life" be considered by those who seek to act in conformity with the AMA guideline?

There is absolutely no way to tell.

The AMA guideline says only that "quality of life is a factor to be considered in determining what is best for the individual." It fails to answer the potentially fatal question of *how* quality of life should be considered, whether simply as A) "the condition or quality of life of the patient, regardless of how it comes about," or B) "in terms of the effect that treatment will have on the patient's quality of life." Both are quality of life judgments; both fulfill the letter and the spirit of the AMA guideline. But which one the AMA intends physicians to adopt is not indicated in the guideline.

This justifies the claim I made earlier that the *New England Journal of Medicine's* charge that the Baby Doe regulations are only a "set of general rules, which are of necessity insensitive and vague" is a case of the pot calling the kettle black. The medical profession's own guideline in this area is also "vague and insensitive"; worse, it is literally and quite dangerously equivocal.

If only for the sake of clarity, the AMA should eliminate this equivocation and should adopt new terminology which will indicate precisely the Association's intention in this critical matter. Without such clarification, the current AMA guideline obscures the issue rather than

affording physicians the sure guidance which they need in this difficult matter.

In addition, this gives the federal government an open invitation to intervene in matters which are not properly its business.

If the medical profession hopes to convince the federal government not to intervene in this matter, it must show the government that the profession's own standard is better than the crude one the government has devised.

At present the medical profession cannot do this.

## V. An Unprecedented Ethic

Revision of the current AMA guideline is necessary for another reason: the two ways in which the present guideline allows quality of life to be considered constitute radically different kinds of judgments which themselves presuppose contradictory assumptions about the rights which men (and particularly physicians) have over the lives of the weak and helpless.

It is one thing to judge, as does the ordinary/extraordinary means standard, that the use of certain medical means will have such a deleterious effect on a patient's quality of life that their use is ethically optional, but it is quite a different thing to judge that another human being's condition or quality of life is so poor that he simply is not worthy of continued life, regardless of the expense or *inexpense* of the means whereby his life can be saved.

Civilized men have always acknowledged the propriety of the former judgment, but they have heretofore considered forbidden to them in principle the judgment of another human being's worthiness to live.

## VI. A New Direction?

Perhaps the AMA's equivocal guideline *is not intended to depart* from the proven tradition. If not, then the AMA should seriously consider rewriting it specifically to eliminate the ambiguity which currently allows it to be employed as such a rejection. This would demonstrate to the present administration that there is no need for it to intervene in matters where it is not really competent.

But if the AMA's guideline *is intended* as a departure from the tradition, then this, too, should be clarified by a revision of the equivocal guideline. The implications of such a departure are so great that they need to be clearly documented and widely heralded so that no one will mistake the new direction that the medical profession has taken.

Obviously, neither the administration nor large parts of the American public will like this new direction, but at least the issue will be

squarely joined. Perhaps the ensuing controversy will compel the medical profession finally to produce a *reliable* guideline — not another equivocation, but a wise and just standard which will protect the sanctity of life from the effects of ill-considered decisions while leaving families and physicians the discretion they need in determining the course of action which is best for all parties concerned.

## REFERENCES

1. Angell, M., "Handicapped Children: Baby Doe and Uncle Sam," *New England Journal of Medicine*, 309 (1983), p. 660.
2. American Medical Association, *Current Opinions of the Judicial Council of the American Medical Association* (Chicago: American Medical Association, 1984), p. 10.

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