On Attitudes Toward Death and the Cost of Dying

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An earlier version of this paper was presented at the annual meetings of the Allied Social Science Associations in Chicago in August, 1978. The author, an associate professor at Louisiana Tech University, revised the paper in December, 1978.

The late Andre Hellegers pointed out how elastic the definition of health and, therefore, the definition of health needs has become in recent years. The World Health Organization, stated Hellegers, defines health "as not only the absence of disease, but as the presence of a sense of total physical, mental and social well-being." [1] In the extreme this means, according to Hellegers, that the medical profession must abolish death. A second definition of health is based on the absence of discomfort and, Hellegers stated, logically requires the profession to provide death.[2] A third definition of health views death as natural and urges physicians to accept it.

In this article we attempt to show that there are three distinct attitudes toward death supporting three different types of demand for health services, and that the three types of demand have powerful implications for basic resource requirements and costs. Furthermore, when all of these considerations are viewed in the context of cost-benefit analysis, other implications for such values as the quality of life, a sense of community, and individual liberty follow. Finally, we suggest a way of using cost-benefit estimates which replaces the classification of *persons* as (1) productive and deserving treatment or (2) unproductive and not meriting treatment with a classification of *modes of treatment* as (1) excessively expensive and properly regarded as a gift or (2) not excessively expensive and properly regarded as an individual right and an individual or social obligation.

Abolition of Death

The abolition of death is an attitude that emerged first in the United States at the beginning of the 20th century and is linked historically to the enlightenment of the 18th century.[3] Death is seen as shameful and forbidden; it should be made to disappear.[4] The emergence of this attitude parallels the development of science and technology which supply superior means of survival and, at the same time,

superior means of destruction.[5] According to Elizabeth Kubler-Ross, the new weapons of mass destruction have so increased the fear of death by violent means that man attempts to cope with the reality of his own death by denial.[6]

The spectre of malpractice and criminal prosecution means that, increasingly, the withholding or withdrawing of the latest technology is equated with killing. Third-party payment schemes assure that this technology is widely available. Kubler-Ross suggests that the demand for technological improvements is stimulated by health professionals who, because they are unable to accept death which from their perspective amounts to personal failure, displace their knowledge onto machines. This denial and displacement, in turn, seems to encourage an increasingly mechanical and dehumanized environment in the delivery of health services.[7]

For sure, abolishing death is not the only inspiration for technological change in the health care field. Frequently the same advanced technology is used in ways that truly affirm the value of life. Indeed there are many instances in which sophisticated technological devices are the only means of maintaining life while the patient is being restored to good health.

For that reason, the abolition of death view is not the only factor underlying the vast increases in health care expenditures that are directly attributable to technological change.[8] In those instances where the technology is used to temporarily maintain life, the heavy costs of this technology are properly associated with the saving of life. If, on the other hand, it is used to maintain life when the patient has no prospects for restoration to good health, the heavy outlays are associated with the prolonging of death. Further, if it is employed in a so-called hopeless case over a long period of time, it is proper to asssign these expenditures to the abolishing of death.

Provision of Death

The provision of death is an attitude which views pain and suffering as meaningless and sees death as the final solution to a life that is regarded as devoid of meaning. As with the abolition-of-death position, the provision-of-death attitude is plainly hedonistic.[9] For centuries the provision-of-death attitude has been acted out in the form of suicide and has been publicly allowed in that form in various societies including ancient Rome where suicide was regarded as a proper means for saving face.[10]

Modern interest in the provision of death in the form of euthanasia dates from the 1870s. The euthanasia movement began in Britain in the early 1930s and came to the United States several years later. As recently as 1972 there were no countries whose laws permitted the practice of mercy killing.[11]

In the last few years, however, "death-with-dignity" bills have proliferated in the United States. California enacted the first such law in 1976. Bills of this type were introduced in at least 41 states in 1977. In seven (Arkansas, Idaho, Nevada, New Mexico, North Carolina, Oregon, and Texas), death-with-dignity bills were actually passed. None of the new laws are perfectly alike. In California, for instance, mercy killing is explicitly excluded. In Arkansas, Idaho, and New Mexico, even though mercy killing is not authorized, it is not explicitly prohibited either.[12] According to Grisez and Boyle, all of these bills, whether enacted or not, have two serious consequences. First, they pave the way for homicide by withholding or withdrawing treatment, and, second, they tend to enhance support for directly killing certain patients.[13]

Clearly some of the techniques of providing death (in the form of suicide or mercy killing) are simple and inexpensive, especially by comparison with the techniques of abolishing death. Notwithstanding those vast differences in costs, the provision-of-death attitude and the abolition-of-death attitude are alike in that both put man at the center of the universe by the implicit claim that man is the author of life. In effect, the human body is viewed as property which man may use as it suits him. For the most part this "right" is limited to one's own body. In the case of involuntary mercy killing, however, the "right" to dispose of this property is claimed by another person. In that sense, involuntary mercy killing amounts to the re-establishment of slavery in one of its cruelest forms.

Stanley Hauerwas shows that the provision-of-death attitude, with its emphasis on relieving suffering, has important consequences for medical progress.

> Medicine advances because physicians and those in ancillary professions have been willing to allow others to endure pain, thereby creating the conditions that impel the imagination to explore forms of care not yet conceived.[14]

Hauerwas is neither utilitarian nor sado-masochistic.

> I do not suggest that suffering should be sought for its own sake or that suffering should be accepted as a way of becoming good. Rather, I am trying to suggest that though suffering is not to be sought, neither must we assume it should always be avoided. Often we achieve the good only because we are willing to endure in ourselves and in others an existence of suffering and pain.[15]

Arthur Dyck points to one of the "goods" — a sense of community — which is contingent on certain constraints against killing, suicide in particular.

> Suicide is the ultimately effective way of shutting out all other people from one's life. Every kind of potentially and actually meaningful contact and relation among persons is irrevocably severed except by means of memories or other forms of life beyond death.
>
> An inevitable death can be accepted without guilt; the decision on the part of the dying one that he or she has no worth to anyone can leave tragic

overtones and guilt-ridden doubts for anyone who participated in even the smallest way in that person's dying. . . .

Everyone and every group in a community is potentially a victim of a principle that accepts some lives as unworthy to live; the very young, the very old, and racial and ethnic minorities are especially threatened in a society that accepts such a principle.[16]

Acceptance of Death

The acceptance-of-death attitude has its historical roots in the early Middle Ages.[17] It occupies the middle ground between the extremes of the abolition-of-death view with its high-cost, complex technology and the provision-of-death view with its low-cost, simple technology. It neither prolongs the dying needlessly nor precipitates it directly and intentionally.

Whereas the other two incorporate the property concept of the relationship between person and body, the acceptance-of-death viewpoint incorporates the stewardship concept. Whereas the other two are anthropocentric, the acceptance-of-death position is theocentric. Suffering is regarded as meaningful because one's reward in heaven depends on "the courage and grace, patience and dignity" with which the burden of suffering is shouldered.[18]

The acceptance-of-death view is perhaps best demonstrated by the hospice concept of care for the dying. This concept of care emphasizes control of the patient's symptoms to enable that person to come to grips with his impending death. The collaboration between family and staff in the care of the dying is one important way that a hospice promotes a sense of community.[19]

The hospice concept rejects the high-cost, complex technology that characterizes the abolition-of-death view on grounds that, for the terminally ill, it prolongs the dying needlessly. Figures published in 1976 indicate that the daily charges at the hospice in New Haven, Connecticut are roughly one-half the rate at a general hospital.[20] It also rejects the low-cost, simple technology of the provision-of-death view on grounds that the patient who asks to be killed is not receiving the health care he needs.[21] Hospice care is not expensive. The rate in 1976 at the New Haven facility was $104-108 per day.[22]

The hospice concept is based on the well-known principle that ordinary means of survival are to be provided because those means are the only ones that the patient can claim as being owed in justice.[23] The principle of ordinary means embodies certain normative concepts that are likely to be defined differently by different persons in different circumstances. Even though at times it may be quite difficult to differentiate ordinary from extraordinary means of survival, difficulties of this kind only complicate the application of the principle. They do not *per se* invalidate it.

The proper application of the principle of ordinary means may call for judgment from specialists in fields other than medicine, such as law, economics, and psychology. With regard to economics, it is instructive that the principle of ordinary means is consistent with Heinrich Pesch's principle of satisfying adequately normal human needs. Rupert Ederer translates what Pesch means by this principle as follows:

> The task of the economic process is the optimum satisfacton of peoples' wants that is possible in given circumstances of time and place, where individualized wants are satisfied only with due reference to the general context of wants. [24]

The principle of ordinary means does not imply that the patient may not avail himself of certain extraordinary means of survival. It connotes, rather, that such means need not be provided. Their provision, therefore, is to be viewed not as morally required but as freely given.

Cost-Benefit Estimates: The Conventional Application

The logic of cost-benefit analysis argues that health services be provided to those for whom the benefits exceed the costs and be withheld from those for whom benefits fall short of costs. The coupling of cost-benefit rules and the abolition-of-death viewpoint leads to different outcomes when freedom of choice is allowed and when it is not allowed, unless actually wanting to live is critical to survival. Among persons in need of health services, proportionately more of those who are treated than those who are not will survive whether they freely choose treatment or not. This means that some who are treated will not survive and some who are in need and are not treated will survive. Some, possibly most, of those who are treated and survive will be satisfied with the outcome and others will not. Some of the latter group may become so despondent over the quality of life that they end it by their own hand.

Allowing freedom of choice is likely to be more costly than denying it. Some of those who are in need and for whom the costs are less than the benefits will not choose to be treated and consequently will be more likely to die. Some for whom the costs are greater than the benefits will choose to be treated and consequently will be more likely to live. Clearly, the freedom-of-choice option drives up the cost of an already high-cost delivery system.

The great advantages that derive from implementing the abolition-of-death view is that some persons who are in need of services and are treated will live longer. For some, however, the additional longevity amounts to simply prolonging the dying. Moreover, the complex tech-

nology tends to separate the patient from the staff, thereby dehumanizing the patient. When suicide is permitted, the abolition-of-death view becomes especially destructive of a sense of community.

In principle, the utilitarian logic of cost-benefit decision-making, when it is coupled with involuntary mercy killing, results in certain death for all persons in need of health services for whom the costs of treatment exceed the benefits. Some of those who qualify for treatment under these strict rules will die anyway. Others will survive but may choose later to end their life out of despair as to the compelling requirement to remain productive in order to justify their continued existence. Removing the involuntary mercy killing provision makes for greater uncertainty as to final outcome. Some of those for whom the costs of treatment exceed the benefits will choose life and some of those with benefits in excess of costs will choose death.

The great advantage of the provision-of-death view is found in its cost-containment potential. However, the killing that attends this view, as Dyck points out, is most destructive of a sense of community. Furthermore, involuntary mercy killing spells the end of individual liberty because the taking of a human life destroys all other rights and freedoms of that person.

Cost-benefit rules have an important impact on outcomes when they are linked with the acceptance-of-death view and freedom of choice as to the use of extraordinary means is denied. Under these circumstances only those persons in need for whom the costs are less than the benefits qualify for treatment that employs extraordinary means. Strictly speaking, health care is either owed in justice or it is merited. It cannot be given freely.

At first glance, these rules seem not to affect the outcome when freedom of choice is allowed. However, they do matter importantly and Piper shows us why.

> The possibility — indeed, the necessity — of a consistent policy of manipulating others and calculating their responses as variables in the service of a larger goal reveals a serious problem with the very concept of a consistent Utilitarian doctrine. . . . The first principle of Utilitarianism can be seen as a special case of the non-moral rationality principle of efficient means, in which the particular goal to be most expediently achieved is specified as that of maximizing social utility. . . .
>
> The goal of maximizing social utility is so encompassing that any act performed in an interpersonal context must be evaluated for whether its consequences are relevant to, or constitutive of, its realization.
>
> This means that a concern with social utility must form some part of the motivation of a consistent Utilitarian in any interaction he engages in, indeed in any play of action he undertakes: this is the full sense in which Utilitarianism provides the only rule of conduct for one committed to this doctrine. It may be that some such activities are then found or judged to be irrelevant to furthering social utility. But this can only be a consequence, and not a presupposition, of an evaluation to which every action is initially susceptible. This reveals the extent to which calculation — hence manipula-

> tion — must inform the Utilitarian's every decision, action, and deliberate response.
>
> So if people know that someone is a committed Utilitarian, they are bound to feel somewhat used or manipulated, somewhat suspicious of his manifestations or feeling, involvement with or professed regard for them, and somewhat resentful of his attitude.[25]

The manipulation that inevitably results when cost-benefit rules are employed in the decisions as to the proper allocation of health services is inimical to the virtue of trust which is the disposition most proper to the physician-patient relationship.[26] It follows that cost-benefit rules can be a direct threat to the foundations of a caring health services delivery system.

Cost-Benefit Estimates: A Suggested Application

It does not follow, however, that cost-benefit estimates should never be used in the treatment decision. One of the central problems with the conventional application of cost-benefit estimates in the health services field is that it does not differentiate ordinary from extraordinary means of survival. Further, it classifies individual patients dichotomously: the ones who merit treatment because they are sufficiently productive and the ones who do not merit treatment because they are not sufficiently productive.

This arbitrary classification of persons can be eliminated if cost-benefit estimates are used instead to classify modes of treatment as excessively expensive (extraordinary means) or not excessively expensive (ordinary means). Table 1 displays a scheme for classifying modes of treatment as ordinary or extraordinary according to a comparison of current costs and benefits (row 1) and current and future costs and benefits (row 2) for the individual person in need using personal resources (column 1) and for all persons in need using society's resources (column 2). For example, a mode of treatment which at present is excessively expensive (EE) for a person who is destitute may be classified as not excessively expensive (NEE) for all persons with the same need because of significant differences in the resources available in society. Additionally, the same mode of treatment which is classified as NEE today may be considered EE because of costs that are deferred to the future.

The modes of treatment that are classified as NEE are owed in justice as a corollary from the right to life itself (see our footnote 23). This obligation in justice does not extend to the modes that are classified as EE although such means may be provided as gifts.

For sure, there are serious difficulties that attend the use of the normative concept "excessively expensive." Different definitions will be supplied by different persons in different circumstances. Even so, there are some important advantages that follow from the elastic

TABLE 1. Scheme for Classifying Modes of Treatment as Ordinary or Extraordinary Means: Norm of Economic Burden

Comparison of:	Individuals in Need Using Personal Resources	All Persons in Need Using Society's Resources
Current Costs and Benefits	EE	NEE
Current and Future Costs and Benefits	EE	EE

EE: Excessively Expensive
NEE: Not Excessively Expensive

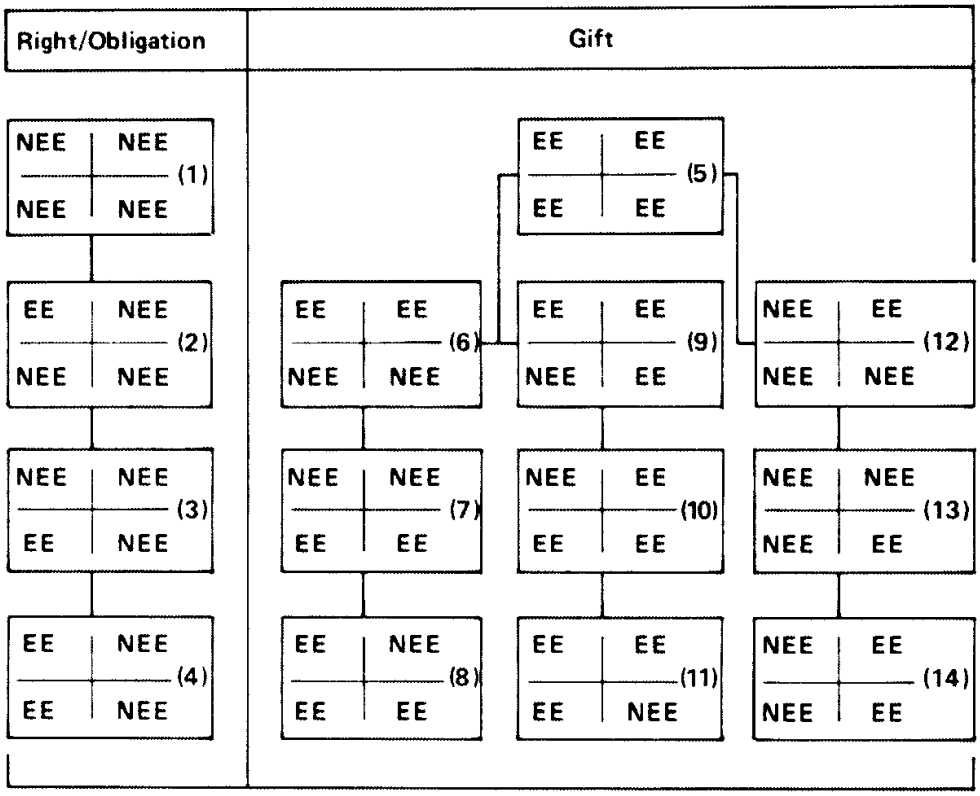
nature of the concept. Surgery such as hip-joint replacement is more likely to be EE in a relatively poor country like Mexico than in a wealthy country like the United States. Further, the definition that applies in a particular place is supplied by those who live there and who will bear the burden and reap the rewards that go with it.

To give precise meaning to "excessively expensive," studies are needed that show the actual costs and benefits for various modes of treatment and kinds of patients. By revealing how various persons and families actually manage their financial affairs when they become sick and are treated, these studies would enable us to specify with greater particularity whether a given service is EE or not.

Using the scheme presented in Table 1, there are 14 classification sets possible for every treatment mode. Applying the principles of subsidiarity, equality, and the common good, along with Pesch's principle of satisfying adequately normal human needs, the 14 sets can be grouped into two broad classes: sets 1-4 and sets 5-14 (Table 2). In set 1 the treatment mode is properly regarded as an individual right and obligation in justice. Sets 2 through 4 are closely related to set 1; the treatment mode is regarded as an individual right and a social obligation. A social obligation need not require government intervention. It may be met through private third-party payment schemes.

In set 5 the treatment mode is properly regarded as a gift. So too is it in sets 6 through 11 which evidence no conflict between the individ-

TABLE 2. Scheme for Determining Whether Treatment Mode Is a Right and an Obligation or a Gift



EE: Excessively Expensive
NEE: Not Excessively Expensive

(1) Individual must provide for own needs and take treatment mode required for survival. Society is not obliged to help individual, although it may have to force individual to take treatment mode required.

(2) Individual cannot afford treatment mode at present, but society can afford it for everyone in need. Treatment mode is social obligation and individual right. Individual must take treatment mode provided by society.

(3) Individual cannot afford treatment mode because of future burden, but society can for everyone in need. Treatment mode is social obligation and individual right. Individual must take treatment mode provided by society.

(4) Individual cannot afford treatment mode because of current and future burden, but society can for everyone in need. Treatment mode is social obligation and individual right. Individual must take treatment mode provided by society.

(5) Treatment mode is EE for individual and society. Individual can refuse to provide or take treatment mode and society is not obliged to provide it. Treatment mode may be provided as gift by one individual to another, or by society to various individuals selected at random to reflect basic equality of those in need.

(6) Treatment mode is EE in terms of current burden. Individual can refuse to provide or take treatment mode and society is not obliged to provide it. Treatment mode may be provided as gift.

(7) Treatment mode is EE in terms of overall burden. Individual can refuse to provide or take treatment mode and society is not obliged to provide it. Treatment mode may be provided as gift.

(8) Treatment mode is EE for individual and society when current and future costs and benefits are evaluated in terms of resources available. Individual can refuse to provide or take treatment mode and society is not obliged to provide it. Treatment mode may be provided as gift.

(9) Treatment mode is EE at present for individual and society. Individual can refuse to provide or take treatment mode and society is not obliged to provide it. Treatment mode may be provided as gift.

(10) Treatment mode is EE when current and future costs and benefits are evaluated in terms of resources available. Individual can refuse to provide or take treatment mode and society is not obliged to provide it. Treatment mode may be provided as gift.

(11) Treatment mode is EE at present for individual and society. Individual can refuse to provide or take treatment mode and society is not obliged to provide it. Treatment mode may be provided as gift.

(12) Treatment mode is NEE for individual who is required to provide and take it. However, it is EE for society at present. Common good argues that society limit individual freedom. Conflict is resolved by allowing only certain individuals, selected at random, to exercise their right. Under these circumstances treatment mode becomes gift.

(13) Treatment mode is NEE for individual who is required to provide and take it. However, it is EE for society when current and future costs and benefits are evaluated in terms of resources available to society. Common good argues that society limit individual freedom. Conflict is resolved by allowing only certain individuals, selected at random, to exercise their right. Treatment mode becomes a gift.

(14) Treatment mode is NEE for individual who is required to provide and take it. However, it is EE for society at present and overall. Common good argues that society limit individual freedom. Conflict is resolved by allowing certain individuals, selected at random, to exercise their right. Treatment mode becomes gift.

ual and society. Sets 12 through 14 are like set 5 in the sense that the treatment mode is regarded as a gift. They are unlike the others because they reflect conflict between the individual and society which is resolved by the application of the principle of common good.

A final step in the research to evaluate the health care system in terms of the health needs of persons who would otherwise die involves a determination as to whether or not the system actually delivers what is owed in justice and if not, what modifications are necessary to assure that the ordinary means of survival are routinely available. Further, research should be conducted to determine if the health care system is being coerced into delivering services which are properly classified as extraordinary means of survival since health services that are delivered under coercion cannot be regarded as gifts. If such coercion exists, the system requires modification that would end such abuse but would still allow the practice of extraordinary means that are freely given.

In our judgment there is no compelling evidence that the U.S. health care delivery system requires additional public intervention to meet the health needs (properly understood) of persons *in extremis*. Indeed, if such intervention were to fail to recognize the difference between excessively expensive and not excessively expensive treatment modes, it is quite possible that health care costs will escalate at a rate higher than the current one. Accordingly we suggest that the resource allocation system offering the best promise of controlling the rising cost of health care is one that uses market prices to allocate resources among competing uses and one in which all payment schemes acknowledge the essential difference between excessively expensive and not excessively expensive means of survival.

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