

# **Ethical Issues in Starting and Stopping End-Stage Dialysis**

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by

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## **Introduction**

Three ethical principles currently determine both law and practice with respect to starting and stopping dialysis in end stage renal disease cases: Medical Futility, Respect for Life, and Patient Self-determination. Even where dialysis is not medically futile, patients possessing capacity, and patients lacking capacity but with valid, functioning proxy decision-makers, self-determination is the dominant principle, in that efforts to prolong and preserve life may be set aside or not initiated at the request of the adequately informed patient or the patient's proxy, both presumed conclusively to be acting in the patient's own "best interests." Where the patient lacks capacity and there is no proxy, Respect for Life dominates, and we are required to initiate and continue dialysis that is not medically futile, except where there is available clear and compelling evidence that the patient would not want life prolonged with dialysis, as in an advance directed or documented conversation.

This category of patients — those lacking capacity who have given neither advance directives nor designated proxies — constitutes a continuum of cases. "At one extreme is the patient who will actually be harmed by dialysis — that is, the effects of dialysis will cause damage to other functions, or will cause significant increase in pain and suffering that would not occur absent the dialysis. In such situations, it can be said that [initiation of] continuation of dialysis is not medically reasonable,"<sup>1</sup> or is medically futile. The middle portion is the range of "difficult cases . . . where the therapeutic value of dialysis is

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1. Susan Goldberg, Magavern & Magavern Law Firm, memo to Buffalo General Hospital Ethics Committee, Dated April 17, 1991.

negligible, difficult to predict, difficult to measure, or outweighed by the negative burdens imposed by the treatment.”<sup>ii</sup> The other end of the continuum is constituted by those cases where dialysis clearly serves the prolongation of life, but care-givers and families question whether the life is worth sustaining.

We are currently in a situation of social policy and law in New York State where only patients or their properly acting agents, after being fully informed of the medical facts, can determine whether the life in question is worth preserving. Absent a major legislative reorientation of our collective ethics and social policies, but two possibilities remain: refining the criteria for the middle portion of the continuum of cases to provide a list of indicators of medical inappropriateness or futility that could be used to assist the decision of whether to begin or continue dialysis; and loosening the requirement of clear and convincing evidence of the patient’s wishes so that evidence pertaining more to the patient’s beliefs, life style, and general values would be acceptable bases for determining the patient’s best interests.

### **Considerations Toward Refining Criteria for Medical Futility**

I suggested earlier that it would be helpful to develop a list of criteria or indicators that could be used to assist the decision of whether to begin or continue dialysis. Such a list, of course, is a set of indicators of medical futility. The literature on medical futility has grown enormously in recent years, spawning a number of candidate definitions. Lawrence Schneiderman of the University of California at San Diego and his colleagues suggest that treatment that fails to provide benefit to the patient, whether or not it has a negative effect, is futile. Any treatment that merely preserves permanent unconsciousness or fails to end total dependence on intensive medical care should be regarded as non-beneficial and therefore futile. The quantitative, statistical side of Schneiderman’s proposal is that treatments with less than a 3% chance of providing benefit should be deemed futile.

It is important to note that benefit, a concept applying to the person as a whole, is distinct from effect, a concept that may apply to some part of the patient’s body. Pearlman reminds us that such a statistical regularity has to be relativized to different categories of patients. Nelson suggests that futility involves more than failing to produce physiologic functioning, and adds

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<sup>ii</sup>2. *Ibid.*

considerations of burdens of needless pain and suffering. And Wear and Freer express doubt that a widely-accepted, readily applicable set of criteria for medical futility is foreseeably forthcoming, and urge instead the preventive approach of actively encouraging physicians to take the time to assist patients confronting chronic disease to develop advance directives, to execute DNR orders, and to designate proxies. Noe echoes this sense that physicians have not generally employed the available mechanisms for patient self-determination, and that hospitals assume only a passive role in providing forms but no systematic direction for their completion.

It seems clear that a more proactive attitude on the part of end-stage renal disease physicians and facilities, perhaps utilizing video presentations and self-explanatory literature, should help lower the number of cases where patient interests and wishes are unclear. Unfortunately, even with the most aggressive preventive ethics, there will still remain a significant residue of patients for whom proxies and clear advance directives are unavailable. It is to these that I now turn.

### **Toward Broader Understanding of Patient's Wishes and Best Interests**

The cluster of principles that defines the ethical and legal stance toward medical decision-making taken in New York State reflects, I believe, the experiences of our citizens and their ancestors over decades and centuries. The high premium placed upon individual autonomy is a social antidote to the imposition of quality of life decisions in tyrannical regimes such as the Third Reich, in which first the lives of the physically and mentally handicapped, and then the lives of individuals characterized by various racial features, were deemed not worth saving, not worth living. It also reflects the strong egalitarianism of Judeo-Christian ethics, under which all humans, despite differences in ability and station, are conceived to be children of God. Finally, it reflects the pluralism of value traditions that New Yorkers bring to their collective policies in that we collectively endorse values shared universally and permit within those broad parameters great individual liberty in their pursuit and fleshing out of the set of values by which a given individual determines a life and its preferences.

This cluster, of course, is what determines the legislative and judicial reticence to accept quality of life judgments made by other parties through substituted judgment. The power to render an evaluation that a life is no longer worth living is so great that we have decided collectively that none but the person whose life is the subject of such evaluation shall be empowered to make

it effectively —and then only under conditions of capacity, informedness, non-coercion, non-delusion, and a host of other qualifiers.

The requirement of clear and convincing evidence of the individual's wishes in the circumstances of the present discussion, so far, has tended to involve a search for either written or conversational communications of wishes explicit and specific enough to be seen by most parties to apply to the actual situation. The Hospital Ethics Committees on which I have served have begun to accept under the clear and convincing standard a wider range of evidence than written or oral expressions. Let me illustrate these broadened categories of evidence with a few cases.

A patient, rendered partially paralyzed and mute by a stroke, indicated with a scissors-like movement of two fingers against his feeding tube that he wanted it removed; further, after his family told him he would have to “sign a form,” he spent long hours laboriously practicing his signature. After assuring himself that the patient understood the consequences of such removal, the Committee found that the patient had provided clear and convincing evidence of his wishes.

An elderly nursing home patient who had for years consistently refused medical diagnosis and treatment for a suspected cancer and who resisted medical treatments of most kinds, and who had made declarations such as “There's a time to life and a time to die” when asked if a peg tube could be placed to improve nutrition, and who expressed extreme anxiety and agitation whenever efforts were begun to transfer from the nursing home to the hospital for treatment, was deemed to have clearly and convincingly expressed her wishes not to have the peg tube placed.

The family of a gentleman who, due to advanced Alzheimer's disease and an accompanying stroke, had lost the ability to swallow, convinced the Committee that his life under the conditions of total care by strangers was burdensome to him in the extreme, by discussing the high value he had placed upon personal appearance and health throughout a lifetime of dedication to matters of diet, skin care, and other health regimens practiced for decades.

Thus, families and physicians have the ability to seek support for decisions to end or not initiate various treatments thought to be essential to continued life, by presenting to institutional ethics committees well-developed characterizations of the non-linguistic behaviors expressive of values and beliefs of patients as developed and practiced over significant portions of their lives. Non-treatment decisions thus become authenticated against a set of beliefs and practices which are expressions of that patient's self-determined best interest,

even if those beliefs and values have not been verbally articulated in written or oral communication. Moreover, the period reviews of hospital and nursing home patient records by the state Department of Health serve as a check against unreasonable construals of patient behaviors, as do the possibilities of unaccepting relatives or care-givers challenging Institutional Ethics Committees' findings in the courts.

### **Institutionalizing broader criteria state-wide**

It is unfortunate that, absent any collective sharing of the findings of Hospital Ethics Committees, such advances in the evidentiary findings of one committee are unlikely to have much impact on the overall behavior of institutional ethics elsewhere in the state.

I can think of two remedies for this lack of shared wisdom. One would be the systematic collection and publication by, say, the State Department of Health or the New York Task Force on Life and the Law of the minutes of Hospital Ethics Committees that embody and express particularly apt examples of reasoning. Promulgation of those cases would make available to others the rationales of committees that have successfully reasoned their way through difficult situations. The second way of sharing the wisdom of such decisions would be for periodic conferences to which institutions would be invited, or perhaps required, to send representatives, where such cases and issues would be presented and discussed. Perhaps the New York Academy of Medicine will consider instituting regular conferences of this sort.

### **Reopening the Definition of Death Debate**

There is one final option for dealing with the middle are of our continuum of patients lacking capacity. At least some of the troublesome cases that have brought us together today are patients in permanent vegetative, comatose states, not at all likely to recover, suffering from a host of conditions including end-stage renal disease. Some years ago medicine and law combined forces to rethink our definition of death; the whole brain death criterion of legal death was the result. A declaration of death can be made now for a patient on cardio-pulmonary life support who meets a set of complex criteria. At our hospital in Buffalo, we have added to those receiving legislative approvals one that seek to relativize the finding of death to the belief system of the patient and the patient's family. Thus, those with what I would characterize as more vitalistic beliefs — where spontaneous vital functions in any of a number of organ systems apart from the brain are regarded as signs of the patient's continued life — are accommodated in determining the time at which death is declared and post-mortem activities may be begun.

We have lived with that whole brain death criterion for some time. it has permitted us the harvesting of some organs that otherwise would be lost awaiting the permanent cessation of spontaneous heartbeat and respiration. it has permitted us to escape the technological traps of resuscitated patients who were brain dead not being able to be taken off "life support" legally. However, the whole brain death criteria has encountered limitations in the case of anencephalic newborns, and in the case of victims of decerebrating event that have left portions of only the brain stem intact. As well, it has not benefitted individuals who suffer from what I would call mid-brain isolation: the

disconnection of cortex from all sensory and motor pathways: such include, it now appears, Karen Ann Quinlan.

Cases such as these, with the exception of the Quinlan case, are ones in which there is a strong sense among many that there is no person, no person any longer. I for one cannot distinguish in terms of the presence of a person and over the long haul, between someone who is brain dead but warm, on a respirator, but never regains consciousness, and someone who lacks a function cortex, has an intact brain stem, is warm, not on a respirator, but never regains consciousness. The immediacy of unconscious dependence on cardio-pulmonary life support differs from the protracted unconsciousness of the patient with only a Still-functioning brain stem, but not in a way that counts in terms of significant human qualities or their potential for human activity. There may be some point to distinguishing between the dying patient and the dead patient in these circumstances, but it is perhaps only one of compassion for those who must struggle with accepting the diagnostic finality of either pronouncement: “He’s dying,” “She’s dead.”

I suggest a reopening of the debate on the cortical death criterion of a person’s death. Technology is increasingly able to maintain individuals who have no cortical life in the grey zone between robust life and the finality of death. Just as we found an enormous difference between asking relatives of an individual who was brain dead whether they would consent to the removal of the respirator, and informing relatives of such an individual that death had occurred and that the respirator would accordingly turned off, so we may find that informing the relatives of an individual that has suffered irreversible and total cortical destruction — or even, if your diagnostic powers are great enough, of irreversible cortical destruction sufficient to make consciousness no longer possible, that the loved one is dying — will suffice to ease the acceptance of the wisdom and, I would argue, the moral requiredness, of withdrawing those technological measures which, when temporarily needed are modern miracles, but when become permanent ways of life constitute a torturous purgatory for families and care-givers, dangling hopeless hope, delaying the onset of final grieving, and condemning care-givers and loved ones to protracted pretense in the shadow of a meaningless penumbra.

There will, of course, be those who do not share this view. For them, as under the present definition of death, it will be possible to deflect the normal consequences of a diagnosis of dying, and retain commitment to a technologically supported, vitalistic way of life. But my sense is that the vast majority of Americans would welcome relief from the common apprehension

that the end of life may well consist of a protracted period of unconscious dying. So, my challenge to the institutions of medicine and law is this: just as you successfully redefined “death,” so it is now time for you to take up the task of defining “dying.” “Dying” as a frank diagnostic category may well offer a way out of the present technological impasse that can only grow in size as technology advances in its ability to hold death at bay.

### **Notes**