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Nutrition, Hydration and Cost Containment

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The *New England Journal of Medicine* has been the launching pad for numerous bioethical trial balloons over the years. Death as the treatment of choice for handicapped newborns was first suggested in print in the pages of this prestigious journal by Duff and Campbell in 1973 and as late as 1984, the imprimatur of publication was accorded to apologists for *third trimester* abortion. The publication of "The Physician's Responsibility Toward Hopelessly Ill Patients" (Wanzer, S. et al. *NEJM* 310:955, 1984)¹ must be scrutinized with this record as a background. There are 10 different authors from 10 different institutions and, not unexpectedly, much of the article is based on an apparent consensus of different backgrounds and widely separated geographical locations. As such, the article is largely platitudinous and exhorts the profession toward a level of care in informed consent already in place and accepted without controversy in most places.

The placid landscape of pious pronouncements, however, is disturbed toward the end of the article by a somewhat muted explosion. After a slight nod to assisted suicide, the authors state that it is "ethically permissible" to withhold "nutrition administered by . . . gastric tube" from "severely and irreversibly demented patients" as well as those who are "pleasantly senile."

It is obvious that the issue of the ethical permissibility of removing feeding tubes is highly controverted in medical as well as legal circles. The *Claire Conroy* case in New Jersey resulted in a decision that to remove the tube would be unacceptable because it would result in death from "a new and independent condition: dehydration and starvation." The Supreme Court of New Jersey overruled the lower court and said that feeding could be discontinued if a) a living will so directed; b) the patient verbally directed the doctor to do so, or c) the physician determined that the burden of continuing feeding outweighed its benefits.

The last point is fraught with danger in that it allows the attending physician to determine when it is in the patient's best interest to be dead.

In the widely publicized Herbert case in California, two physicians were acquitted of a charge of murder after having taken a patient off of a respirator and having removed his feeding tube. The basis for the murder charge, however was the allegation that the removal of respirator support and tube feeding had been carried out in an inappropriately hasty manner on a patient whose coma had resulted from possible medical malpractice. The survival of such a patient could result in the award of a judgment far in excess of that resulting from his early death. The Herbert case, then, does not clearly support the removal of any and all feeding tubes on terminal patients in California. The crux of the matter is whether the tube feeding constitutes ordinary or extraordinary care. Wanzer and his co-authors apparently base their position on the dubious notion that the insertion of a feeding tube is more uncomfortable than death by starvation for the "severely and irreversibly demented" patient or the "pleasantly senile" patient.

This category of patient is, of course, quite separate from the terminally ill, persistently vegetative, or brain dead patients (even in the authors' classification in the article). "Dementia" is in no way synonymous with "dying", even if it happens most often to senile patients of advanced age.

Health care planners with a cost-benefit orientation would be delighted with a national policy allowing the removal of feeding tubes and the withholding of antibiotics from the *entire class* of demented, senile patients in institutions. Savings in the billions could probably be achieved annually. The cost in human terms, would be much greater. The American system would slide further down the slippery slope of death worship.

Most Illustrious Medical Publication

The *New England Journal* is America's most illustrious medical publication. It does not, of course, establish standards of care and none of its authors can claim to speak *ex cathedra*. It would be ingenuous, however, not to expect that the principles enunciated in this article would impact heavily on the national conscience.

Those who deplore the "slippery slope" type of argumentation will have to concede that there is a progression in permissiveness from the recommendation that feeding be withheld from a) "brain dead" patients b) patients in a "chronic vegetative state" c) "irreversibly demented" patients and, finally, d) "pleasantly senile" patients. There is also demonstrated here the tendency of a principle to expand to cover a multitude of sins. The principle employed in various contexts is the "Right to Privacy."² This principle, unexpressed in the Constitution but alleged, by the Burger Court, to be implied in the fifth and fourteenth Amendments, was enunciated as the pregnant woman's "right to privacy" in reproductive decision-making which allowed her to abort her child without the interference of law.³ In the Baby Doe case in Bloomington, Judge Premo, in the Indiana lower court, enunciated a parental privacy right to choose one form of therapy over another. This right was said to

extend to the private right to choose the option of death by starvation for Baby Doe over the option of life-saving corrective surgery.⁴ The Right to Privacy now being invoked is the private right to refuse medical treatment. The principles underlying this right can be summarized as follows:

1. A competent patient has the right to refuse care even if refusal means certain death.
2. The wishes of a once-competent patient, as expressed in writing or verbally to friends or relatives, must be accorded great weight after he has become incompetent.
3. When the patient is a child, parents' decisions should be respected except when they are not in the child's best interest.
4. Physician will be protected if his concurrence in a decision to withhold treatment is a good faith judgment in conformity with generally accepted medical standards.
5. Where a once-competent patient never expressed a preference, if a treatment is excessively burdensome or does not offer a reasonable hope of benefit, it may be eliminated.

This latter balancing of burdens versus benefits is sometimes referred to as the principle of proportionality. The principle of proportionality was enunciated frequently by the President's Commission for the Study of Ethical Problems in Medicine in various contexts.⁵ It was also adopted by the California Appellate Court in the Barber case⁶ and is employed by various authors in the medical literature.^{7,8} It is frequently cited as a calculus to be preferred over the traditional "ordinary" versus "extraordinary" means of prolonging life. It would seem, however, that the differences are more semantic than substantive. A therapy imposing more burdens than benefits would be "extraordinary" and a therapy offering more benefits than burdens would be "ordinary". In fact, Pius XII, in his epoch-making address to the anesthesiologists, alludes to burdens and benefits while defining the distinction between ordinary and extraordinary means.⁹

Factors in Patient's Medical Condition

It is obvious that the benefit/burden equation is relevant to the decision to withdraw nutritional support and that the application of the principles of proportionality will be contingent on the medical condition of the patient.

1. If the patient is *brain dead*, there is obviously no benefit to be derived from continuing nutrition except in those instances where it might be maintained briefly for the benefit of harvesting organs for transplantation.
2. If death is imminent, in the sense that it will occur with or without treatment, in a short time, the provision of nutrition would be ineffective and therefore could be withheld in those instances where it could only be provided with great difficulty.¹⁰ Connery has suggested that "imminent" in this context means two weeks or less.

3. If the patient is in a *persistent vegetative state*, the discontinuation of hydration and nutrition would be highly questionable. A patient in a persistent vegetative state is not presumed to be dying. The prognosis for the regaining of consciousness and cognitive function is generally presumed to be hopeless. However, in one highly publicized case, Sgt. David Mack of Minneapolis regained consciousness after 22 months of coma, to testify that he had been aware of happenings around him for six months.¹¹ Najenson, in studies of Israeli servicemen in coma as a result of injuries suffered in combat, concluded that the prognosis could be improved by doubling the dose of calories usually provided.¹² He concluded that the cause of death was likely to be either aspiration or starvation. By increasing feedings, and keeping patients upright, he achieved a 70% rate of recovery. Whatever the prognosis, however, the duty to prolong life is not abrogated by a hopeless prognosis. As Connery has pointed out, "A patient may live a long time with a hopeless disease. One cannot simply argue that the disease is incurable and thus no obligation exists to preserve life."¹³ Brodeur, on the other hand, argues against perceiving quality of life and sanctity of life as polar opposites. He states, "If life has a spiritual value to which temporal ends are subordinated, how does the permanent comatose patient pursue these ends? If a pure physiological existence ensues, which is what happens to a person in a persistent vegetative state, does a moral obligation to continue life sustaining treatment still exist?"¹⁴ The inference may be drawn that a person not in pursuit of spiritual values may be leading a less than meaningful life. To paraphrase, "Let he who is leading a full spiritual life pull the first plug."

The problem in deciding about nutritional support for the chronically comatose patient, may derive from the classification of food and drink as modalities of medical treatment. As Meilaender has pointed out, "The care involved in feeding is not, in any strict sense, medical treatment, even if provided in a hospital. It is ordinary human care and is not given as treatment for any life-threatening disease."¹⁵ Viewed in this light, feeding is neither useless nor excessively burdensome. As strategies for providing nutritional support have become more complicated, there has been a tendency to evaluate them along with other invasive technologies such as respirators and dialysis machines. It is probably more valid to view self-feeding, assisted feeding, nasogastric tube feeding, hyper-alimentation, and gastrostomy feedings as strategies for providing basic support for persons capable of varying degrees of cooperation. (The decision to use one or the other may be related as much to staff convenience as patient competence. It may be a lot quicker to feed by tube rather than teaspoon.) The benefit of feeding for the permanently comatose patient is the preservation of his life even if he has no capacity for life with the quality of consciousness. If anything,

the burden of providing nutrition is reduced by the advancement of technology (such as the technology of introducing flexible gastrostomy tubes by way of endoscopy).¹⁶

4. *Irreversibly demented patients and pleasantly senile.* We mention these categories only to condemn the rationale of using such categories as an excuse for withholding food and water. Neither category justifies the withholding of nutritional support, the tortured rationale of the Wanzer group notwithstanding.¹⁷
5. *Problem of Pain.* Justification for the removal of nutritional support is often included under the rubric of shortening a painful existence. The British Medical Research Council¹⁸ has reported in a long study, that pain can be relieved without shortening life. An adequate number of drugs has been shown to be available for control of pain of varying severity¹⁹ but these are apparently underutilized.²⁰ Withholding food and drink leads to death by starvation and dehydration. Dehydration leads to death through hemoconcentration, hyperosmolarity, azotemia and hypernatremia.²¹ Thirst and hunger to the extreme will be experienced to the degree that the patient is conscious and aware of these sensations. In summary, death by starvation is painful. Pain resulting from terminal illness can be controlled without shortening life. As Ramsey has pointed out, relief of discomfort is a primary objective of the physician caring for the terminally ill.²²

Legal Aspects

Myers has summarized the legal arguments for continuing patient nourishment, as follows:

1. Nourishment is included within that minimum level of care that anyone has a right to expect to be continued.
2. The expectation of certain minimal care, including nutrition, is essential to the maintenance of trust and confidence in the physician-patient relationship.
3. The dignity of the patient requires that hydration and nutrition continue, even when other care is withdrawn.
4. Artificial nourishment can be provided in a simple non-invasive manner.
5. Nourishment is not medical treatment but a basic necessity of life.
6. To withdraw nourishment causes death by means independent of the underlying illness.
7. Nourishment allows life to continue while the illness runs its course.
8. Withdrawal of nourishment is beyond the powers of the surrogate decision maker.
9. Few, if any, patients express, in advance, a desire not to be fed.
10. To withdraw food and water is to cause a painful, agonizing death.²³

Most of the above arguments are subject to refutation in a court of law. The death of Karen Quinlan in June of 1985 reminded the nation of

her remarkable survival for over nine years after she was removed from a respirator and provided comfort care only, including tube feedings. Karen had originally lapsed into a coma following an ingestion of an unknown combination of drugs. The etiology of the coma was unknown and the prognosis, therefore, unsure. In November, 1975, Judge Muir refused the Quinlan family permission to remove the respirator. In March, 1976, the New Jersey Supreme Court overruled Judge Muir, stating that an individual's right to privacy is "broad enough to encompass a patient's decision to decline medical treatment under certain circumstances."²⁴ Although the Quinlan family never petitioned the court to remove her feeding tube, many of the subsequent decisions can be considered Karen Quinlan case law progeny.

Three Feeding Tube Cases

The three principle feeding tube cases are the Clarence Herbert case, the Claire Conroy case and the Paul Brophy case. The facts of these cases are summarized in Table I.

Since the Wanzer article is unquestionably the watershed publication on the issue of discontinuing feeding for certain classes of patients, we must examine the contents carefully for what seems to be a pro-euthanasia bias.

1. On the issue of assisted suicide, for example, the paper seems to be on both sides of the issue. It says, "Although a rare patient may contemplate suicide, the physician cannot participate by assisting in the act, for this is contrary to the law." The subliminal message is that there is regret about the law. The next sentence states, for example, "On the other hand, the physician is not obligated to assume that every wish (for suicide) is irrational and requires coercive intervention." From an ethical standpoint, the fact that suicide is against the law is the least important reason why it should not occur. The authors of the Wanzer article imply that while we regretfully cannot assist suicide, we should not work too hard to prevent it. The article, then, walks a fine line between an endorsement of euthanasia and the responsible choice to refuse therapy when its burden far outweighs its benefit.²⁵ It is important to note, for example, that the conferences upon which the paper is based were held under the auspices of the *Society for the Right to Die*. This is the latest name for the group which was known from 1938-1967 as the *Euthanasia Society of America* and from 1967-1975 as the *Euthanasia Educational Council*. The important distinction, in this instance, is between *what* is done and *why* it is done. The Vatican Declaration on Euthanasia in 1980 states, "By euthanasia is understood an action or omission which of itself or by intention causes death."²⁶ The terms of reference for euthanasia, then, are to be found both in the intention of the will and in the methods used.

The authors state that "financial ruin of the patient's family as well as the drain on resources for other patients who are not hopelessly ill, should be weighed in the decision-making process." Cost containment is thus given a prominent place in the evaluation of therapy. Some Catholic authors

boldly assert the propriety of including cost containment in the hierarchy of values even in our society where no need to triage patients has been demonstrable.

The danger of this emphasis is two-fold. First of all, there is no such thing as inexpensive medical care. The attempt to delineate the difference between ordinary and extraordinary care on the basis of cost alone in an affluent society, is almost impossible. (I recently spent a few short days in the hospital for a relatively minor surgical procedure and used up the entire annual salary of a person who would be considered to be above the poverty level.)

The second danger is, of course, the new categories for therapeutic restriction created by the Wanzer group. They go beyond those with terminal illnesses, beyond those in a persistent vegetative state to address a group known as the "pleasantly senile." They define this group as those with "a permanent mild impairment of competence, somewhat limited in their ability to initiate activities and communicate but who appear to be enjoying their moderately restricted lives." Members of this group are also described as "biologically tenacious" meaning, apparently, that they are not able to accept Governor Lamm's suggestion that they drop dead.

"Freedom from Discomfort" Recommended

All that is recommended for this group is "freedom from discomfort." If emergency resuscitation and intensive care are required, "they should be provided sparingly", based on, among other things, "the wishes of the patient's family and the prospects for improvement." They recommend that routine monitoring of vital signs should be stopped, diagnostic testing should be stopped, antibiotics should be stopped. Then the clincher: "Food and water given *naturally or artificially* (emphasis added) may be provided or not depending on the patient's comfort." When we see how the "pleasantly senile" category is defined, it is obvious that feeding anybody above a certain age becomes an option rather than an obligation under the principles of the Wanzer group and the Right to Die Society. Deciding not to treat the elderly, whose competence is only mildly impaired, is a quantum leap away from not resuscitating the terminally ill or not prolonging the dying process. It is an ugly, unconscionable step down that slippery slope to active euthanasia.

The society has identified two goals for the care of the chronically and terminally ill: a) cost containment and b) death with dignity. The medical control of nutrition has been held out as a way of accomplishing both of these goals simultaneously. Daniel Callahan, director of the Hastings Institute, has noted: "Given the increasingly large pool of superannuated chronically ill, physically marginal elderly, denial of nutrition could well become the non-treatment of choice."²⁷

Medicare spending increased seven-fold from 1970-1982. It now costs the taxpayers \$55 billion and may go broke by 1990. In that context, these proposals could be viewed as a particularly nasty kind of cost-cutting. The

elderly have enough worries without wondering whether their attending physician is about to label them pleasantly senile and write them off.

Should "health care planners" have anything to do with decisions to withhold treatment? Even to suggest that they do reflects a monumental change in the nature of medical practice in the United States. The medical profession must resist the tendency for its allegiance to drift from the patient to the paymaster.

As recently as three years ago, the idea that fluids and nourishment might be withdrawn with legal and moral impunity would have been repudiated and condemned by most health professionals.

The underlying philosophy is as follows:

1. That for a growing population of patients, the costs and burdens of continued life are perceived as being too great to justify the continuation of life support.
2. Death is accepted as the outcome to be desired for such patients.
3. The physician is to be the agent bringing about the desired outcome.

The countervailing philosophy would be as follows:

1. The discontinuation of fluids and food should be forbidden except in rare instances where it can be incontrovertibly demonstrated that the problems of maintaining nutrition clearly outweigh the acceptance of death by starvation. This philosophy should prevail until there is much more certainty that denying nutrition will not lead to inevitable calamities for the society.

The benefits of adhering to this alternative philosophy would be as follows:

1. Patients will be protected. Prognosis for term of survival is one of the least accurate and least scientific medical skills even where the diagnosis is clear and accurate.
2. Society will be protected. The fabric of society is threatened by a drift toward the unscrupulous restriction of care out of cost benefit consideration.
3. Physicians will be protected. There is evidence that physicians are much more inclined to provide fluids and nutrition in terminal situations than so-called professional ethicists. Three out of four physicians polled by Micetich, et al.,²⁸ expressed a desire to provide nutrition even to terminal, unconscious patients.
4. The Hippocratic tradition against direct euthanasia will be preserved for the medical profession.
5. The role of the physician as patient advocate in quality of life debates will be maintained.
6. The goals of medical therapy can be prioritized to include provision of comfort and amelioration of severity as well as complete recovery.

Most physicians would identify the care of the elderly and the terminally ill as a largely unsatisfactory part of the total picture of American medical

care. The United States wins the lion's share of Nobel prizes for medical research and American medicine is on the cutting edge of advances in high technology diagnostic and therapeutic achievement. The hospice movement has represented a welcome development toward the humanization of the care of the terminally ill. In all candor, however, it must be admitted that the level of care in American nursing homes and extended care facilities is more an occasion for scandal than for satisfaction. The quality of life for the elderly in these institutions provides, in the eye of the beholder, an inspiration for short-term, Draconian solutions. The society which groans under the burden of providing acute care under Medicare has been unwilling to accept the reality that personal and financial disaster are still a part of the system for those whose terminal illness escapes the time frame of acute care. As the makeup of the society changes toward the inverted pyramid of an aging population, the need for the medical profession to address the deficiencies of chronic care will increase. As Mark Siegler has said, "If care is to be withheld, it should be withheld from those who are strongest and most powerful for they are the ones who can make the best case for themselves. The aged and incompetent cannot speak for themselves and should, therefore, not have to bear the burden of justifying their continued medical treatment."²⁹

One person in nine is now over 65. By the 21st century, it will be one in five. There have been suggestions that everyone on Medicare be required to have a living will. The National Conference of Commissioners of Uniform State Laws has approved a Model Living Will statute which includes the provision of food and water under Medical Treatment.³⁰ During their deliberations in Minneapolis, the Conference defeated an attempt to restrict the definition to *artificially* administered nutrition and to exclude nutrition provided *naturally*.

Dr. Andre Wynen of Belgium, the Secretary General of the World Health Organization, expressed the following well-grounded fear.³¹ "Now that cost containment in health care is an everyday threat to the basic interest of the patient, the conflict calls for the presence of his natural defender, the doctor, to help him against the self-interest of the majority. Just as the lawyer defends an accused in society, so must the doctor defend the patient against his own family when the welfare of the elderly or handicapped is at stake."

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Civil Law Court Decisions

- I. *State of California* - The Case of Clarence Herbert, age 55, died Sept. 6, 1981:
 - 1) Within the three days, August 25-28, 1981, tests and examinations indicated that Mr. Herbert had suffered severe brain damage, leaving him in a vegetative state, which was likely to be permanent.
 - 2) Thereafter, he was taken off the respirator, all blood work and all intravenous fluids were terminated, and finally the nasogastric tube was removed.
 - 3) As of August 31, he received no further nutrition, hydration or medication. From that point until his death, Mr. Herbert received only nursing care which preserved his dignity and provided a clean and hygienic environment.

- 4) *Decision of the Court of Appeal of the State of California, Oct. 12, 1983:*
 - A. The use of an intravenous administration of nourishment and fluid, under the circumstances, is the same as the use of the respirator or other form of life support equipment.
 - B. A treatment course which is only minimally painful or intrusive may nonetheless be considered disproportionate to the potential benefits if the prognosis is virtually hopeless for any significant improvement in condition. (See generally President's Commission, Ch. 2, pp. 82-90.)
- 5) *Decision seems to be based on a "quality of life" judgment.*
2. *State of New Jersey - The Case of Claire Conroy, age 84, died Feb. 14, 1983:*
 - 1) At the time of trial, Feb. 2, 1983, Ms. Conroy suffered from arteriosclerotic heart disease, hypertension, and diabetes mellitus.
 - A. Her left leg was gangrenous to her knee; she had several necrotic decubitus ulcers (bed sores) on her left foot, leg and hip.
 - B. An eye problem required irrigation.
 - C. She had a urinary catheter in place and could not control her bowels.
 - D. She could not speak and her ability to swallow was very limited.
 - E. She interacted with her environment in some limited ways.
 - 2) Ms. Conroy was not brain-dead, comatose, or in a chronic vegetative state.
 - A. Both doctors testified that if the nasogastric tube were removed, she would die a painful death of dehydration within a week.
 - B. The medical judgment was that even with treatment she probably would die within one year. Death was not judged to be imminent.
 - 3) *Decision of the Superior Court Judge Reginald Stanton, Feb. 2, 1983*, was that Ms. Conroy's life had become impossibly and permanently burdensome, and that removal of the feeding tube should therefore be permitted. The guardian *ad litem* appealed.
 - 4) *Decision of the Appellate Court, July 8, 1983*, overruled the lower court's decision, concluded that withdrawal of Ms. Conroy's nasogastric tube would be tantamount to killing her - not simply letting her die - and that such active euthanasia was ethically impermissible. N.B.: Claire Conroy died before this decision was rendered.
 - 5) *Decision of the Supreme Court of New Jersey, Jan. 17, 1985*, held that to remove the nasogastric tube in particular cases, the medical evidence must establish that the patient fits within the Claire Conroy pattern: an elderly, incompetent nursing-home resident, with severe and permanent mental and physical impairments, and a life expectancy of approximately one year or less.
3. *State of Massachusetts. The Case of Paul Brophy:*
 1. Patient was a paramedic for the Eastern Fire Department
 - a. Patient had suffered a ruptured intracranial aneurysm in 1982.
 - b. His wife, a nurse, petitioned court for permission to remove gastrostomy tube.
 - c. Family stated that Brophy had, on several occasions, made clear his wish not to be kept alive artificially should his condition become hopeless.
 2. Court denied permission to remove gastrostomy tube
 - a. Court held that artificial feeding is neither invasive nor painful and that discontinuation of feeding would cause painful death.
 - b. Competent person has a general right to refuse treatment under appropriate circumstances.
 - c. Brophy's desires, as expressed on his behalf by his guardian, were outweighed by the state's interest in preserving Brophy's life.
 3. Court distinguished the circumstances of the Brophy case from other cases covering terminal illness in that
 - a. Brophy is not terminally ill.

- b. If Brophy were dying, it might be permissible to remove his tube as a response to family's "substituted judgment".
- c. Court would not decide that Brophy's life is not worth preserving.
- d. The quality of life is an incorrect focus because there are no manageable criteria for making such a judgment.

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