

Questions Surrounding the Withdrawal of Artificial Hydration and Nutrition from Patients in a Persistent Vegetative State

Daniel E. Deaton, M.Div., M.A.R., Th.M.

Dr. Deaton is serving as chaplain at the Naval Hospital in San Diego where he is a member of the bioethics committee. He holds the M.Div. and M.A. degrees from Gordon-Conwell Seminary and a Th.M. from Princeton Theological Seminary.

In 1950, Rita Greene was working as a nurse at Washington, D.C., General Hospital when she contracted tuberculosis from one of her patients. She then became a patient at the hospital where she was treated for about one year. On October 25, 1951, the day before she was to be released, Greene suffered a cardiac arrest and lapsed into a persistent vegetative state (PVS). Since that day, she has lain motionless and unconscious in room 5221 of D. C. General, where she has been kept alive through artificial hydration and nutrition (AHN) administered by private duty nurses who also turn and bathe her. She is believed to be the longest surviving PVS patient in the United States.

The American Academy of Neurology defines PVS as:

"...a form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiological sleep/wake cycles, but at no time is the patient aware of him- or herself or the environment. Neurologically, being awake but unaware is the result of a functioning brainstem and the total loss of cerebral cortical functioning."

This total loss of cerebral cortical functioning may have been caused by a variety of insults to the brain. Among these are "nutritional insufficiency, poisoning, stroke, infections, direct physical injury, or degenerative disease." PVS patients are incommunicative, cannot experience pain, and are incontinent of urine and stool.

It is not clear how many patients, like Rita Greene, are victims of PVS. Neither is it known what it costs for the

life-sustaining technology and care to keep these patients alive. Estimates range from 5,000 to 25,000 PVS patients in the United States at any given time, with the costs of uncomplicated PVS care ranging from \$2,000 to \$10,000 per month per patient, depending on the site (home, hospital, or chronic care facility), type of nutrition (enteral or parenteral) and the region of the country where the care is provided. The one area of agreement is that the number of PVS patients is growing and will probably continue to grow with the advancement and application of trauma care and high-technology medicine.

The care and management of PVS patients raise significant ethical questions. These involve the reliability of the diagnosis of PVS and the possibility of recovery, the definition of death, the issue of whether AHNM should be considered as treatment or care, the burdensome costs and consequences of such care, and the question of when, if ever, it is ethically acceptable to terminate AHN of a PVS patient. The aim of this paper is to bring these issues under scrutiny from the point of view of Christian ethics.

Affirmations and Presuppositions

In order to consider the issues outlined above, I offer the following framework of affirmations and presuppositions which I believe form a valid (though not exhaustive) grid through which to view these (and some other) problems in medical ethics.

1. Human life is made in the image of God and is a gift as a trust from Him.

God assigns value to human life. He gives it and He takes it away. We are the stewards of our lives, and we are held accountable by Him for the choices we make all through life and not just at its end stages. To choose death by suicide or "euthanasia" is a fundamental rejection of this first affirmation.

2. Death is a reality because of the entrance of sin into the human race.

Death is an enemy to be fought even though for the Christian death has been transformed into the entrance to a glorious eternity. Nevertheless, there is a time to die and there exists no duty pointlessly to prolong dying. Physical longevity is not the supreme value to be increased at all other costs.

3. Treatments may legitimately cease when there is no benefit or reasonable hope for the patient's recovery.

Proper medical treatment is not always to be equated with maximum treatment. Care in the forms of comfort and company must always be given to those with no natural hope of recovery, but not that which only prolongs the dying process. Treatment that is very costly, unusual, dangerous, difficult, or which causes serious or painful side effects disproportionate to any clearly curative benefits may be discontinued.

4. Patients have the right to refuse treatment when they are competent to do so, and their legally appointed surrogates may do so for them when those patients become incompetent or voiceless.

This is not to accept the so-called "autonomy" of the patient. It is to recognize the individual's personal responsibility to make informed decisions about his or her own care. This right is relative to other concerns and is not a right to ruin one's health or to cease ordinary curative treatments which have a reasonable hope for success. The patient, or his or her legally appointed surrogate, has the right to free and informed participation in medical decisions affecting him or her when there are alternative treatments.

5. All decisions to continue or forego any particular treatment depend on the patient's present condition and

the best objective medical determination on the part of the physician or physicians making the diagnosis.

Paul Ramsey suggests the term "medically indicated" best describes appropriate care. It is not based on "quality of life" judgments or notions about what life is "meaningful." The issue is the "comparison of treatments to determine whether they are likely to be beneficial in any way other than prolonging dying."

6. The same treatments that were potentially life saving when begun, can, after further medical diagnosis, become means for aimlessly prolonging dying.

The dying patient may at times need to be protected from relentless medical intervention when such intervention was begun with the expectation of a cure but over time was determined to be futile. The same standard of "comparison of treatments" given above applies also to the decision to continue curative treatment or discontinue its use. The initiation of treatment, whether in an emergency or non-emergency setting, does not imply or require its continued use. Information that was unavailable at the initiation of treatment or the deterioration of a patient's condition may be factors that allow for withdrawal of "life support" or other forms of treatment.

7. Decisions to treat or cease treatment are not infallibly made. Where the prognosis is uncertain, or different courses of treatment or non-treatment are recommended by the care givers, responsible third parties not involved in the treatment should be consulted.

This affirmation applies especially to decisions made on behalf of voiceless patients or incompetents who must depend on surrogates to make these difficult decisions for them.

8. In situations where the correct course of treatment or non-treatment is unclear, the application of the Golden Rule ("Do to others as you would have them do to you" Luke 6:31) is appropriate.

This is not an endorsement of "situation ethics" or a subjective method of making decisions by some

nebulous appeal to "love." It is merely the recognition that God commands us to act on behalf of others in a manner consistent with how we would like to be treated. When we are not morally obligated to take a given course of action, we should be guided by our wishes for ourselves.

9. Food, air and water by natural routes are necessary means of the preservation of life and may not be denied to any patient.

Food and water taken through the mouth and air breathed on one's own are not forms of medical treatment to be withheld from anyone. The deliberate withholding of food and water from someone who is capable of ingesting them in order to hasten his or her death is immoral.

AHN and the PVS Patient

With the above affirmations and presuppositions in mind, the possibility of withdrawal of AHN from certain PVS patients may be considered by posing and answering several questions.

1. How reliable is the diagnosis of PVS, and what is the likelihood of recovery from it?

The primary methods of diagnosis of PVS involve careful and extended clinical observation of the patient along with laboratory studies. PVS patients will show "no behavioral response whatsoever over an extended period of time." No voluntary action or behavior is observed in a PVS patient. He or she awakens and sleeps cyclically, but shows no behavioral evidence of being able to respond in a learned manner to external events or stimuli. Despite appearances of alertness at times, PVS patients "repeatedly fail to demonstrate coherent speech, evidence of comprehension of the words of examiners or attendants, or any capacity to initiate or make consistently purposeful movements."

In addition to behavioral observation, positron emission tomography is used to determine the metabolic rate for glucose in the cerebral cortex. In PVS patients, such a rate is greatly reduced to a level inconsistent with

consciousness or the capacity to experience pain. Brain imaging tests (CT scans) sometimes also reveal lesions or cortical atrophy, depending on the cause and duration of the condition.

Taken together, the above diagnostic criteria provide a very high degree of certainty in the diagnosis of PVS. The more difficult issue is the determination of the permanence of the state. This depends on the nature of the brain injury, the age of the patient, and the period of time the loss of cognitive function has already lasted. Both the American Medical Association and the American Academy of Neurology agree, however, that once PVS has lasted three months, recovery of consciousness is very rare and the condition can reliably be considered permanent.

Patients under 40 years of age have the best possibility of regaining consciousness, although the likelihood is still very small. The American Medical Association's Council Report on PVS concludes:

Even in young persons who have experienced head trauma, a conservative criterion for the diagnosis of PVS would be observed unawareness for at least 12 months. Cognitive recovery after 6 months is vanishingly rare in patients older than 50 years. If the handful of reported occurrences of cognitive recovery in patients with PVS are divided by the total estimated number of PVS cases in this country, the odds of recovery are less than 1 in 1000. The risk of prognostic error from widespread use of the above criterion is so small that a decision that incorporates it as a prognostic conclusion seems fully justifiable.

Based on the above, I conclude that the diagnosis of the permanence of PVS is reliable, though not infallible. After a patient has been in PVS for one year, the possibility that he or she will recover seems to be statistically minute. Those diagnosed to be in a permanent PVS due to atrophy of or severe physical trauma to the cerebral cortex may be judged to be beyond the possibility of natural recovery of

consciousness.

2. Should the definition of death be expanded to include those diagnosed to be in a permanent PVS?

Some ethicists have suggested that the definition of death be changed from a whole-brain death criterion to the criterion of the "permanent loss of sentience." Under this definition, further treatments of patients diagnosed in permanent PVS would not be required, since such patients would be considered dead as persons even though their bodies were biologically alive.

Although this would solve the dilemma of AHN of PVS patients, I do not think it is a wise approach. A person without sentience is still a person, although a very ill one. To make a distinction between a person and his or her body opens the possibility of further redefinition of death to include, perhaps, those who have limited capacity for awareness such as Alzheimer's sufferers or severely retarded persons. It is wiser to define death as "the irreversible loss of heart, lung and brain function -- to make each a necessary criterion and all three together the sufficient criteria for declaring someone to be dead."

No one "recovers" from the above defined state of death. Those who have suffered temporary or permanent loss of sentience ought not to be considered among the dead.

3. Can AHN ever accurately be considered as treatment?

This difficult question has been debated widely and forcefully. At first glance, it would seem that AHN should be placed in the category of ordinary palliative care never to be denied anyone. Those who take this view maintain that to withhold hydration or nutrition even when it must be administered artificially is to kill the patient deliberately by dehydration or starvation.

Such a view carries much weight yet seems to ignore the very obvious parallels between AHN and other mechanical interventions such as respirators, dialysis machines and even antibiotic therapy.

The most common methods of AHN are the nasogastric tube (threaded through the nostril and into the stomach), the gastrostomy tube (surgically inserted into the stomach), the jejunostomy tube (surgically inserted into the small intestine), and the intravenous (IV) line into the bloodstream (seldom used for the long term AHN needed for PVS patients). All of these devices are invasive, require supervision of highly trained personnel, are accompanied by risks and side effects (e.g., infection, bleeding, diarrhea, electrolyte imbalances, pneumonia, fluid overload, etc.) and are costly. Unlike the giving of a cup of water or bowl of soup, these feeding procedures can reasonably be viewed as medical treatments not ethically and unequivocally mandated for every patient.

For the vast majority of patients, AHN is a very beneficial temporary therapy allowing for the treatment of medical problems when the taking of food and water by natural routes is not possible. AHN also allows time for the clarification of diagnosis over a longer period as in the case of PVS patients. The presumption should therefore always favor the initiation of AHN in patients for whom death is not irreversibly imminent. However, the initiation of AHN does not imply or require its continued use irrespective of its efficacy for the recovery of the individual patient.

4. When may AHN be withdrawn from a PVS patient?

The decision to cease treatment by AHN ought never to be taken lightly. The PVS patient is totally dependent on the judgments of others for his or her care and is among the most vulnerable in our society. The focus should always be on the patient.

It should also be noted that a decision permitting the withdrawal of AHN does not make it morally obligatory. Respect should be given to families and care-givers who conscientiously object to the withdrawal of AHN and they should never be required to act against their consciences. Families willing to accept the burdens and costs of indefinite AHN should be permitted to move the PVS patient to a facility where such treatment can be carried out.

With those observations in mind, AHN of PVS patients

may be ethically withdrawn when there is no natural and reasonable hope that the patient will recover. When a PVS patient is reliably known to be in an irreversible condition, treatment is no longer medically indicated since it is no longer of benefit to him or her.

A conservative and prudent method of determining irreversibility would be to require a team of neurologists who have previously not been involved in the diagnosis or treatment of the patient to examine him or her after he or she has remained in a PVS for a period of at least one year. Using the diagnostic criteria outlined in question one above, the team may determine, with certainty in some cases and overwhelming probability in others, that the individual will not recover from the PVS.

The family or legally-appointed surrogate for the patient may then decide whether or not to withdraw AHN on the basis of the patient's known wishes, their own informed judgment, or the application of the Golden Rule. Such a decision need not be made hastily and should reflect, if possible, the unanimous view of the immediate family if they are making the decision. In any case, the family is not under obligation to continue useless or futile application of AHN. It may be withdrawn, not because of some "quality of life" judgment, or by defining the patient as already dead, but because it offers no benefit toward the recovery of the patient. In these narrowly defined situations AHN can be seen as serving aimlessly to prolong dying for patients in whom there is no reasonable and natural hope for recovery.

5. Since death results from withdrawing AHN, isn't this a form of euthanasia, and a painful one at that?

The issue of pain is irrelevant to the PVS patient, since those in PVS lack the cortical function needed to experience pain. However, the accusation of euthanasia is a serious one to which a plea of "not guilty" is entered.

It should be noted that certain other medical treatments are withdrawn in some circumstances despite the fact that death will result as certainly as with the withdrawal of AHN. Among these are renal dialysis, blood

transfusions, respirators, etc. In these cases it should be acknowledged that the underlying disease or injury that initially required the life supportive treatment is the cause of death and not the withdrawal of treatment which has been deemed useless. The withdrawal only seems to be the cause of death. Death would have invariably occurred had the treatment not been initiated in the first place. Withdrawal of life support affects the timing of the death, but is not the cause of it. The intent of withdrawal is not to cause death but to cease treatments that offer no reasonable curative benefit. Death follows as a result of the patient's fatal pathology.

6. Doesn't the withdrawal of AHN from certain PVS patients open the door for the withdrawal of AHN from other groups of patients?

The possibility of abuse of any principled ethic always exists but in this case the danger is particularly acute. Because of this, Daniel Callahan has questioned the withdrawal of AHN even when it might be ethically legitimate in order to preserve a "moral emotion" and "repugnance against starving people to death." Daniel Avila, Staff Counsel for the National Legal Center for the Medically Dependent and Disabled, has suggested that withdrawing AHN will lead to death by lethal injection.

While I acknowledge the legitimate concerns and fears of the "slippery slope" to euthanasia, this danger can be guarded against without requiring treatments whose only effect is a pointless prolonging of dying for an irreversibly and incurably ill patient.

It is essential that both law and medical practice distinguish between those patients whose cortical function is totally and irretrievably lost and other persons who may have minimal or severely impaired consciousness. The principle of the sanctity of human life would require a most vigorous protection of the latter group.

The position of this paper affirming the withdrawal of AHN from some PVS patients is not based on a "quality of life" ethic that might jeopardize other patients' right to life. It is based on the curative futility of the treatment, not the quality of the PVS patient's life.

Given the present diagnostic reliability as I understand it, I have proposed a waiting period of one year (instead of three months as the American Academy of Neurology suggests) for the determination of whether a PVS patient is known to be in an irreversible unconscious condition. This proposal is designed to make certain that the patient's unconsciousness is not temporary, and that there are no lingering remnants of sentience. This one-year period is admittedly a conservative precaution designed to prevent premature withdrawal of life support and defend against the intrusion of "euthanasia" where the diagnosis is uncertain.

Summary and Conclusions

The vast number of life-sustaining treatments available today forces us to be part of exceedingly difficult decisions about our own dying and death of our loved ones. These agonizing decisions require our best ethical judgments as we apply the unchanging word of God to the ever changing circumstances and dilemmas of the modern world. Knowing our fallibility we seek God's wisdom while depending on His grace when we fail to apply His truth accurately to all the facets of each problem.

Because of my intentional focus on the individual patient, I have not discussed related issues such as the emotional and financial burdens falling to the families of PVS patients. While I have eliminated these considerations as the ground for the withdrawal of AHN, they are important concerns. The pointless prolonging of dying through AHN in patients who are completely and permanently unconscious unquestionably generates profound emotional pain for the families as well as immense financial burdens.

When these financial responsibilities cannot be met, they fall to the public sector, adding to the costs of health care and increasing public debt. Rita Greene, who was mentioned at the beginning of this paper, has been sustained in a PVS for over forty years with the costs of her care at D.C. General (a public hospital) covered by a workers' compensation claim. These and related issues need to be debated and studied from an ethical

standpoint before financial considerations bring about the rationing of health care merely on the basis of utilitarian or cost/benefit theories.

The withdrawal of AHN from anyone, even the permanently unconscious, may seem to be a cruel and insensitive act. Yet in his book *The Patient as Person*, Paul Ramsey suggests that permanently unconscious patients may be among those few patients who are "irretrievably inaccessible to human care." He writes:

If there are cases of neglect and defect of care for the dying, there may also be not an excess but a now useless extension of care. Acts of charity or moving with grace among the dying that now communicate no presence or comfort to them are now no longer required.

If that is so, we can properly withhold AHN in the narrowly defined cases I have described without fear of weakening the responsibility to protect and save human life, and without being accused of callous indifference to the patient in a permanent PVS.

Persons with total loss of cortical function are incapable of suffering hunger, sensing comfort or experiencing companionship. It is strange logic indeed that would require one to give to a patient what he or she cannot receive. Such actions may produce psychological benefit for the care giver, but they are matters of complete indifference to the patient.

By focusing on the patient, we can do what is appropriate for him or her while avoiding the useless and costly extension of treatment when there is no hope of recovery.

Endnotes

1. McCormick, Brian, "Not Enough Data on Lives, Costs," *American Medical News*, January 7, 1991, p. 23.
2. Executive Board, American Academy of Neurology, "Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient." *Neurology*, Vol. 39, Jan. 1989, p. 125.

3. Council on "Scientific Affairs and Council on Ethical and Judicial Affairs, "Persistent Vegetative State and Decision to Withdraw or Withhold Life Support," JAMA, Vol. 263, Jan. 19, 1990, p. 427.
4. Ibid.
5. McCormick, op cit., p. 23. See also Ronald E. Cranford, "The Persistent Vegetative State: The Medical Reality (Getting the Facts Straight)," Hastings Center Report, Vol. 18, February/March, 1988): pp. 27-32.
6. Frame, John M., Medical Ethics: Principles, Persons and Problems, Presbyterian & Reformed Publishing Company, 1988, p. 66.
7. Ramsey, Paul, The Patient as Person, Yale University Press, New Haven, 1970, pp. 122-123.
8. I refer here to chapter three of Tom L. Beauchamp and James F. Childress, Principles of Biomedical Ethics (New York: Oxford University Press, 1989). The authors, following John S. Mill, define autonomy in a way that overrides other legitimate safeguards to the prevention of suicide and the protection of human life.
9. Ramsey, Paul, Ethics at the Edges of Life, Yale University Press, New Haven, 1978, p. 157.
10. Ibid., p. 168.
11. Ibid., p. 178.
12. Ibid., p. 272.
13. Withdrawal of life support or other treatment may seem to be the cause of the patient's death, when in fact such treatment was only delaying the dying process brought about by the injury or disease afflicting the patient. The perception that withdrawal of treatment causes death may prevent the legitimate termination of useless treatment.
14. Payne, Franklin E., "Counterpoint to Dr. Davis on the Brophy Case," Journal of Biblical Ethics in Medicine, July, 1987, pp. 59-60.
15. Report of the Heroic Measures Committee, Presbyterian Church in American General Assembly, 1989.
16. Executive Board, American Academy of Neurology, p. 125.
17. Council on Scientific Affairs and Council on Ethical and Judicial Affairs, p. 427.
18. Executive Board, American Academy of Neurology, p. 125.
19. Council on Scientific Affairs and Council on Ethical and Judicial Affairs, p. 427.
20. Executive Board, American Academy of Neurology, p. 126.
21. In 1981, a Japanese team of Neurosurgeons did a five-year follow-up study of 110 PVS patients and found that 73% of them had died in that period. Only 5 of the 110 were considered recovered at all. Of the 5, three could not communicate or move about. The remaining 2 recovered their cognitive abilities to a large degree. It should be noted that this study was done before some of the present diagnostic tools were being used. See K. Higashi, et al., "Five Year Follow-up of Patients With Persistent Vegetative State," Journal of Neurology, Neurosurgery, and Psychiatry Vol. 44, 1981, pp. 552 -554.
22. Council on Scientific Affairs and Council on Ethical and Judicial Affairs, p. 428.
23. See, for example, Daniel Wikler, "Not Dead, Not Dying? Ethical Categories and Persistent Vegetative State," Hastings Center Report, Vol. 18, February/March, 1988, pp. 41 - 47.
24. A good critique of this approach is offered by John M. Stanley, "More Fiddling with the Definition of Death?" Journal of Medical Ethics, Vol. 13, 1987, pp. 21 - 22.
25. Frame, John M., Medical Ethics, p. 61.
26. One writer calls this a "cowardly version of euthanasia" and compares it to the practice of Phoenician crucifixion. See John M. Dolan, "Death by Deliberate Dehydration and Starvation: Silent Echoes of the Hungerhauser," Issues in Law and Medicine, Vol. 7, Fall, 1991, 173 - 197.
27. See Bernard Lo and Laurie Dornbrand, "Understanding the Benefits and Burdens of Tube Feedings," Archives of Internal Medicine, Vol. 149, September, 1989, pp. 1925 - 1926. Clinical aspects of AHN are also discussed in an article by Katie Maslow, "Total Parenteral Nutrition and Tube Feeding for Elderly Patients: Findings of an OTA Study," Journal of Parenteral and Enteral Nutrition, Vol. 12, September/October, 1988, pp. 425 - 432.
28. In the case of a patient in whom atrophy of the cerebral cortex is evident, it is certain that natural recovery of sentience is impossible. Such certainty may also be possible in cases of severe trauma to the brain where the brainstem remains intact.
29. Holst, Lawrence, E. "Withholding Nutrition and Hydration: Some Old and New Questions," The Journal of Pastoral Care, Vol. 45, Spring, 1991, p. 12.
30. Callahan, Daniel, "On Feeding the Dying," Hastings Center Report, Vol. 13, October, 1983, p. 22.

31. Avila, Dan, "Establishing the Link Between Death by Starvation and Death by Lethal Injection," *Life Cycle*, Vol. 113, April, 1991, p. 8.

32. Davis, John Jefferson, "Concerning the Case of 'Mr. Stevens'," *Issues in Law and Medicine*, Vol. 7, Fall, 1991, p. 241.

33. McCormick, Brian, "Not Enough Data on Lives, Costs," *American Medical News*, January 7, 1991, p. 23.

34. Ramsey, Paul, *The Patient as Person*, p. 161.

35. *Ibid.*, p. 162.

36. It might be argued by some that the mere receiving of the nutrition by the physical body is a good in itself without regard to the patient's consciousness. This would be true if there were any reasonable possibility that consciousness would be regained. Since that is not the case with patients in a permanent PVS, the mere maintenance of bodily life is futile. The maintenance of organic life is instrumental to the conscious personal life for which God created us. For a good treatment of this issue, see John Jefferson Davis, "Concerning the Case of 'Mr. Stevens'," *Issues in Law and Medicine*, Vol. 7, Fall, 1991, pp. 237 - 240.

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