

THE PVS PATIENT AND THE FORGOING/ WITHDRAWING OF MEDICAL NUTRITION AND HYDRATION

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OVER THE LAST several decades modern medicine has progressed at a rate that has astonished even its practitioners. Developments in drugs, vaccines, and various technologies have given physicians an incredible amount of success over disease and morbidity, as well as allowing them to make dramatic interventions into the body to repair or replace a problematic system or organ. Yet there are limits we are coming to recognize slowly and only reluctantly. For even many of our best technologies are only halfway technologies, i.e. the technology or intervention compensates for a function but cannot cure the underlying pathology or correct the damaged organ. The respirator is probably the most frequently encountered example of this phenomenon.

Another intervention is our capacity to provide nutrition and hydration to those in a persistent vegetative state (PVS). For long-term feeding of such individuals, a gastrostomy tube is inserted directly into the stomach and the liquid protein diet is delivered in a controlled fashion by a pump. If the individual is reasonably healthy and other reflexes are intact, the life expectancy may be several decades.¹ The PVS will not be cured, and the liquid protein serves to maintain the status quo. The question of how to treat these patients medically is now heavily debated nationally and internationally.

In this essay we will examine the issue in several ways: (1) report on a survey of the U.S. hierarchy on bioethics committees in general and on forgoing or withdrawing nutrition and hydration in particular; (2) propose a structured argument which includes a reconceptualization of "quality

¹ The longest case of coma is that of Elaine Esposito, who died 37 years and 111 days after falling into coma. See The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions* (Washington, D.C.: U.S. Government Printing Office, 1983) 177 n. 16.

of life" judgments; and (3) offer suggestions for the future conduct of this debate.

A SURVEY OF THE U.S. HIERARCHY

General Analysis

In January of 1988 one of the authors (TAS) developed a brief questionnaire which sought information on two broad areas: (1) Were there diocesan bioethics committees and, if so, what was their composition etc.? (2) Did dioceses have specific policies on the issue of nutrition and hydration?²

One hundred and sixty-seven questionnaires were sent to the ordinaries of the U.S. dioceses. Seventy-eight ordinaries responded. Of these, 62 indicated that there was no diocesan bioethics committee; 16 indicated the existence of such a committee, and of these, 7 sent in detailed information which will be evaluated separately below.

Of those indicating no diocesan committee, 8 said that there were committees at local Catholic hospitals. Another 8 identified a specific individual within the diocese to whom the ordinary turned for assistance. Another 3 indicated the formation of such a committee, either on a diocesan or on a state level. One respondent stated there was an inoperative committee.

The survey then asked for a description of the membership of the committee, frequency of meetings, its role, whether or not there were guidelines, and how it functioned within the diocese. Committee size ranged from 9 to 23 members, which allowed for a good representation of professions, typically including hospital administrators, physicians, nurses, chaplains, ethicists, lawyers, and other theologians. Six of the committees met monthly, 2 bimonthly, and 1 as needed. Three respondents said their role was to set policy, 2 were to be advisory, and 1 was to be primarily educational. Two respondents had no guidelines, and 9 indicated some form of guidelines ranging from church teachings on medical issues to specific pronouncements of the hierarchy over the past decade.

Part 2 of the survey focused specifically on the moral evaluation of feeding tubes. Of the 78 answering, 17 made no comment on Part 2, 37 made some comments, and 22 respondents reported no cases of PVS patients in their diocese.

Nine respondents reported knowledge of PVS patients within their

² Some dioceses may not have received a survey either because the see was vacant or because of error on TAS's part. Additionally, not every respondent answered every question. Thus, in terms of data analysis there is no constant "n"; yet an overall impression can be gained from the data.

dioceses. Of those 9, 8 reported figures ranging from 1 to 4-5 per year, and 1 respondent indicated 10 cases in the past year. Eight committees were asked to consider cases and 11 had not been asked. Additionally, 4 respondents reported that they have specific guidelines they follow in such instances and 8 indicated that they have none.

The survey asked if the committee considered feeding tubes to be a medical technology. Six said yes, 4 said no, 8 gave no answer, and 1 said "it depends." The respondents were then asked if they considered the use of such feeding tubes to be routine care. Six said yes, 4 said no, 8 gave no answer, and 1 said "it depends." The next question was whether the removal of a feeding tube from a PVS patient was ordinary or extraordinary, or if they had no position. Four responded that the care was ordinary, 4 that it was extraordinary, 1 had no position, 9 gave no answer, and 9 said "it depends." The final question asked whether removal was an act of involuntary euthanasia which is direct and forbidden, or indirect and permitted, or no position. Four responded that removal was direct, 5 that it was indirect, 2 had no position, 4 said "it depends," and 8 had no answer.

Before turning to an analysis of the seven detailed responses (Documents A-G), we would like to make a few general observations about the data so far.

Given the seriousness of contemporary bioethical questions and their pervasiveness within society, it is surprising that so few dioceses have these committees or that so few local Catholic hospitals were indicated as having one. While neither seeking to bureaucratize all life nor to reject appropriate patient and family autonomy, nonetheless such committees on a diocesan or state level serve a useful function, minimally by providing workshops or other resources to hospitals or other groups in the diocese. Of those that are in place, the composition is well represented from a disciplinary perspective, and the committees meet with appropriate regularity. The committees appear to be accessible and, while maintaining patient privacy and confidentiality, there is some degree of openness in the committees.

Part 2 of the questionnaire provides more interesting data. Nine committees had cases brought to them; taken together, they had a moderately large number of cases, about 45. Six committees considered feeding tubes to be a medical technology and also routine care, 4 thought they were not a medical technology, and 1 did not consider them routine care. One committee was uncertain in each case. Yet of these committees, only 4 thought that feeding tubes were ordinary means whose removal constituted active euthanasia.

Four committees considered the technology ordinary and 4 judged it

to be extraordinary. Four thought their removal to be direct euthanasia, while 5 considered it passive euthanasia. But even more interesting is that 9 committees thought that the placing of the technology into the ordinary/extraordinary categories depended on the individual circumstances of the case, and 8 thought the same thing about the determination of active or passive euthanasia. This suggests substantial ambiguity about the moral status of feeding technologies for PVS patients.

First, there is a difference over whether the procedure is a medical technology. If a technology, its moral evaluation fits conceptually more easily into the traditional format of ordinary/extraordinary means. If not, one might have to structure the argument differently. Most interesting are the differences in perception between whether the therapy is considered ordinary or extraordinary means, on the one hand, and whether its forgoing/withdrawal is morally evaluated as direct or indirect euthanasia, on the other. This interest is compounded when combined with the additional judgment—on the part of 9 and 8 respondents respectively—that such a determination “depends” on the circumstances. Such evaluations suggest room for various analyses of the problem and the possible moral acceptability of several resolutions.

Analysis of Specific Guidelines

Seven respondents sent more detailed information about committee make-up and the bylaws governing these committees. We will discuss each document in some detail, but, to maintain a promised confidentiality, we will simply refer to these documents as A–G.

Document A suggests that the primary locus for decision-making is the local hospital, with the diocesan or proposed state-wide committee serving as a resource. Yet part of the task of the proposed state-wide committee will be to develop guidelines for the local committee. At present, discussions are ongoing among committees but no consensus has been reached.

Document A affirms a presumption in favor of the use of feeding tubes but states that each case must be examined on its own merits. On the other hand, in very exceptional and extraordinary cases the withdrawal of feeding tubes might be passive and therefore permissible euthanasia. Thus, while removal of these tubes is exceptional, their removal is not prohibited. As the document states it, “each case must be considered on its own merits.”

Document B represents the responses from three diocesan hospitals, since this diocese has no diocesan committee. B1 indicated that, while there have been cases, the committee did not meet as a committee on them. Rather, individual members of the committee served as resources

to the medical staff and the families. This document stated that there is no consensus within the hospital about the issue, and so each case is to be examined on its own merits. The committee understands the practice as passive euthanasia and thus permissible, but also recognizes that there is no consistent position in the hospital.

We detect a problematic area in this document. B1 argues that feeding tubes might be withdrawn on the basis "that continued treatment *will result in* prolonged total dependence, persistent pain, or discomfort, or in a *persistent vegetative state*" (emphasis added). However, one wonders how the withdrawal of feeding tubes causes PVS. This technology is used to *support* patients in this condition; its administration does not *result* in PVS.

Document B2 states that their consultation has been on the placement of such technologies rather than on their withdrawal. Since it has no fixed policy, each case must be dealt with individually. Additionally, this committee considers tube feeding to be a medical technology and can become an extraordinary means in specific cases "which must be individually assessed and reassessed." The decisions are to be considered in "light of the effect of this nutrition and/or the burden to the patient which would be experienced." Again, these decisions cannot be based on a broad application of a policy but must be made according to "case-specific evaluations."

Document B3 comes from an ethicist at a medical center which has no committee. The respondent indicates that conversations about this problem show that many individuals at the medical center have concerns about the issue. Tube feeding, in this individual's judgment, is a technology, but its moral significance resides in "its function in the ongoing treatment of the patient." Thus the central issue is: Does the treatment contribute to restoring life and health, or does it prolong the patient's dying? "If the former, I think it [is] routinely required. If the latter, I judge it foregoable, permissibly not obligatorily foregoable. . . . Tube feeding in some cases is proportionate, hence required, in others, disproportionate, hence not required."

Two other relevant comments were made by this hospital ethicist. First, can feeding tubes ever be withdrawn? If one can

admit that sometimes tubal feeding need not be *instituted*, then you are already describing conditions which might eventuate *within a case* which justify discontinuing tubal feeding. Put another way, a patient on tubal feeding might become the sort of patient you don't want to begin on tubal feeding. Since you need not start the intervention on the latter patient, why must you stay with it for the former one? (Emphasis in the original.)

Second, never starting or, once begun, removing the tubes is not an

intending of death; rather, these decisions indicate that families "recognize and consent to (accept) a dying process which is judged irreversible and imminent."

The two common themes in these three documents from diocesan hospitals are a recognition of the ambiguities in the issue and a strong affirmation of a case-by-case evaluation. The more crucial moral elements are case-specific and determining the usefulness of the technology in relation to the condition of the patient. In addition, the suggestion to use the same criteria for not instituting the therapy and for withdrawing it is a helpful one and could aid in resolving several problems.

Document C is testimony to a state legislature on a natural-death act. At issue is the inclusion of a proviso for withholding feeding tubes in a living will. After a strong affirmation of the dignity, sanctity, and value of all human life, this document states: "The concern to affirm life, however, does not require the maintenance of physiological life by all means. It is recognized that aggressive overtreatment is as ethically unacceptable as is undertreatment. Both lack respect for the dignity and welfare of each person."

This testimony makes four points that lay out several issues very clearly.

1. A clear presumption in favor of life should be established. People who are able to eat, but only with assistance, cannot be discriminated against or be refused appropriate treatment.
2. The law should recognize the right of individuals to be allowed to die in circumstances where medical treatments, including nutrition and hydration, are ineffective or too burdensome for the patient.
3. The law must carefully define useless or ineffective treatment to clearly identify those treatments that offer no benefit of recovery or no relief of pain. The burdens associated with continued medical treatment should be defined in terms of the burdens that an individual experiences in pursuing the goals or ends of life and not defined by a level of invasiveness that may or may not be associated with forced feeding.
4. The clinical setting distinguishes between nutrition and hydration. Although both terms are used as though they are identical, it should be recognized that individuals may not require forced nutrition while still requiring hydration to alleviate thirst, provide comfort, relieve pain, or provide an open channel for IV medications.

Document C is very nuanced and makes careful distinctions. In particular, the document emphasizes the distinction between basic nutrition and hydration that requires time and effort on the part of medical personnel to feed the patient orally and the medical procedures that

require total parenteral nutritional support (TPN) or invasive medical techniques to provide nutrition and hydration, e.g. insertion of gastrostomy tubes.

Document D comes from a research center whose writings and contributions were mentioned by many respondents as a source of guidance for their committees. Two major points are made. First, forgoing or withdrawing foods and fluids on the rationale of the "assumption that life itself can be useless or an excessive burden" is morally wrong because it is euthanasia by omission. This carries out the "proposal, adopted by choice, to end someone's life because that life itself is judged by others to be valueless or excessively burdensome." The crucial issues here are the moral intention of those who would withdraw the means of providing nutrition, on the one hand, and the justification for the argument adduced to support such a withdrawal, on the other. For this document, the intention is to end life, and the justification for so acting is that the life is burdensome or useless. This constitutes direct euthanasia.

Second, the forgoing/withdrawing of medically provided nutrition and hydration "do not necessarily carry out a proposal to end life." When certain conditions are met—"if the means employed is judged either useless or excessively burdensome"—one may forgo or withdraw treatment.

Nonetheless, *if it is really useless or excessively burdensome* to provide someone with nutrition and hydration, then these means may rightly be withheld or withdrawn, *provided* that this omission does not carry out a proposal to end the person's life, but rather is chosen to avoid the useless effort or the excessive burden of continuing to provide the food and fluids. (Emphasis in the original.)

Two applications follow. If death is imminent, nutrition may become useless and burdensome, whether administered by tube or otherwise. On the other hand, if the patients are not dying, feeding provides a great benefit: "the preservation of their lives and the prevention of their death through malnutrition and dehydration." Yet even in this instance this treatment could become useless or futile: "(a) if the person in question is imminently dying, so that any effort to sustain life is futile, or (b) the person is no longer able to assimilate the nourishment or fluids thus provided."

On the basis of this analysis, Document D concludes:

We thus conclude that, in the ordinary circumstances of life in our society today, it is not morally right, nor ought it to be legally permissible, to withhold or withdraw nutrition and hydration provided by artificial means to the permanently unconscious or other categories of seriously debilitated but nonterminal persons. Food and fluids are universally needed for the preservation of life, and can

generally be provided without the burdens and expense of more aggressive means of supporting life.

This document makes a strong argument in favor of such feeding based on the value of human life, the fact that such feeding can provide benefits to the patient and is not generally burdensome, and that the withdrawal of such technology many times includes the intention to end a person's life. Only when the individual is actually dying and/or cannot assimilate nourishment could the feeding be considered an extraordinary means.

Document E represents an advisory opinion of an archdiocese. This opinion bases its position on Pius XII's teaching on ordinary and extraordinary means, the *Declaration on Euthanasia* of the Congregation for the Doctrine of the Faith, and documents from the Committee for Pro-Life Activities of the National Conference of Catholic Bishops. Document E uses the standards of reasonable hope of success and a determination of excessive burdens as the criteria for decision-making. In addition, it recognizes and accepts the presumption of the use of medically providing nutrition and hydration for individuals.

The advisory opinion makes two statements of importance. The first concerns the decision to forgo or withdraw.

It can hardly be denied that in certain circumstances artificial hydration and nutrition can be just as burdensome and useless as other means and under these circumstances would not be obligatory. A Catholic in good conscience can come to the conclusion that in a particular set of circumstances such treatment need not be initiated or continued, because it holds no hope that it will be successful in prolonging life or is unduly burdensome for oneself or another.

The second point concerns the intention involved in ending treatment. Document E argues that "even though the omission may shorten life, the intention is not to bring on death but to spare the patient a very burdensome treatment." These actions could constitute direct euthanasia if the intention is to end the life; but if omitted because they are too burdensome or useless in preserving life, "they do not constitute killing any more than any other such omission."

Document E uses the categories of ordinary and extraordinary means and then draws the conclusions that a decision to forgo or withdraw nutrition can be made in good conscience and that people should not be prevented from doing what is morally permissible. While the document does not encourage forgoing or withdrawal, neither does it prohibit such actions.

Document F supports the removal of nutrition and hydration within the context of the Catholic moral tradition that permits withdrawal of all medical technologies either on the basis that a patient has entered

the dying phase or that the technologies are nonbeneficial or burdensome. These evaluations are moral as well as medical: "not what will the treatment do . . . , but will the treatment promote human activities and values."

Merely maintaining biological life is not evaluated as being in and of itself humanly beneficial. Life is something more than biological existence. Life is a conditional value which couples biological existence with social, spiritual and human activities such as loving, praying, remembering, forgiving and experiencing. Life is all these things.

Consequently, when these activities can no longer be realized, there is no moral obligation to continue medical treatment, unless to relieve suffering. The conclusion that treatment can stop "does not mean that the person is worthless, but that the person has activated all human potential." Thus there is "no moral requirement to administer artificial nutrition and hydration. In fact it might be violating the person" Document F concludes on the interesting note that "people feel intuitively that it is wrong and want to find ways to escape imprisonment by technology."

Finally, Document G discusses this issue within the context of policies of life-sustaining treatment. The general context for thinking about this issue is:

Prolonging physiological function by itself is not of value if it seems all potential for cognitive functions—mental creativity, the capacity to know and to love—if all that is irreversibly destroyed. Respect for life is at the heart of medicine, and a person in such a condition must not be put to death, but may be allowed to die.

The document then considers various forms of supportive care following the decision to allow to die. First, when medical procedures that prolong life are to be withheld or withdrawn, other medical procedures not directed to supportive care may also be omitted. These include, e.g., lab work, diagnostic procedures, dialysis, nutritional support by mouth or vein, or transfer to an ICU. Measures not to be omitted are "basic nursing care, including patient hygiene, adequate analgesia, oxygen for comfort, positioning, intake for comfort including intravenous hydration, and nutritional support as tolerated." The document then notes that there may be exceptions to hydration and nutritional support.

Exceptions to the last two care elements do exist, especially when they offer no benefit or comfort to the patient. Intravenous hydration may not be appropriate when it prolongs or increases discomfort. With careful deliberation, nutritional support may be withheld when all three of the following conditions are present, namely: (1) The patient has a terminal condition that is irreversible in the final

stages. (2) The patient is comatose and shows no clinical evidence of experiencing hunger or thirst. (3) The patient (or substitute decision-maker) has requested no further treatment. Other situations not meeting the above criteria for withdrawal of nutritional support care will be decided on a case-by-case basis.

Document G concludes that any treatments during this time of dying should aim at maintaining the dignity of the individual and providing compassion and comfort. The guidelines wisely state that the dying are more in need of comfort and company than treatment and diagnostic procedures.

These documents represent a range of opinions, arguments, and conclusions. All are carefully stated, clearly argued, and located squarely within the Catholic tradition. Yet different conclusions are drawn from this common heritage—which indicates that the debate is far from finished. There is strong preference for a case-by-case consideration of the issues and a reluctance to have fixed rules to decide cases. On the other hand, there is a recognition that some consensus needs to be developed. Finally, there is no enthusiasm or joy about the conclusion that forgoing or withdrawing is morally permissible. While the arguments are sound, the conclusion is reached with sadness and reluctance.

In the second part of this paper we turn to our own contribution to the development of a moral consensus by arguing for the permissibility of forgoing or withdrawing medical procedures that provide nutrition and hydration to PVS patients.

ARGUMENT IN SUPPORT OF FORGOING OR WITHDRAWING³

The Medical Situation

An important fact about a PVS patient is that he or she is not dying. In these patients the brain stem is intact, with the major damage to the

³ Throughout the remainder of this essay we have adopted the terminology used by the Hastings Center in describing the technique by which nutrition and hydration are provided to the PVS patient. As defined by the Hastings Center, "medical procedures for supplying nutrition and hydration are medical enteral procedures and parenteral nutritional procedures . . ." "Medical enteral procedures are procedures in which nutritional formulas and water are introduced into the patient's stomach or intestine by means of a tube, such as a gastrostomy tube or nasogastric tube." "Parenteral nutritional procedures are procedures in which nutritional formulas and water are introduced into the patient's body by means other than the gastrointestinal tract. Such procedures include total parenteral nutritional support (TPN), in which a formula capable of maintaining the patient for prolonged periods is infused into a vein—usually a large, central vein in the patient's chest—and intravenous procedures in which water and/or a formula supplying limited nutritional support is introduced into a peripheral vein" (Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* [Briarcliff Manor, N.Y.: Hastings Center, 1987] 140–41).

brain occurring in the neocortex and cortex. Thus these patients breathe spontaneously, have their eyes open, have a sleep-wake cycle, their pupils respond to light, and they typically have a normal gag and cough reflex.⁴

With respect to the diagnosis of PVS patients, there is "no set of specific medical criteria with as much clinical detail and certainty as the brain-death criteria. Furthermore, even the generally accepted criteria, when properly applied, are not infallible."⁵ Furthermore, "It is not uncommon for patients to survive in this condition for five, ten, and twenty years."⁶ Survival is contingent on age, economic, familial, and institutional factors, the natural resistance of the body to disease and infection, and changing moral and social views of this condition.

Of critical importance is knowing whether these patients experience pain and/or suffering. Cranford, following the *amicus curiae* brief of the American Academy of Neurology in the Paul Brophy case, argues that PVS patients "may 'react' to painful and other noxious stimuli, but they do not 'feel' (experience) pain in the sense of conscious discomfort . . .,"⁷ because the centers of the brain required for these experiences are too compromised to be functional. Thus PVS patients are not clinically dying and, if they are otherwise in good health and receive appropriate care, they can have a rather long life-expectancy. We obviously have the medical capacity to provide nutrition and hydration for these individuals, but the ethical difficulty, of course, is whether we must do everything we can to sustain their existence in this clinical condition.

The Value of Life

Clearly the preservation of life is an important goal of the human community in general and of the profession of medicine in particular. Intuitively we know life is valuable and sacred; for were it not, then nothing else would be. Yet, when all is said and done, especially in the Christian framework, life—even human life—is not of ultimate value. Philosophically and politically, we affirm a variety of values that transcend human life: justice, freedom, charity, the good of the neighbor, etc. On the basis of these values or for their sake, we can qualify our protection of individual human lives. Theologically, only God is of ultimate value;

⁴ For a more detailed discussion of the condition of a patient in persistent vegetative state, see Ronald E. Cranford, "The Persistent Vegetative State: The Medical Reality (Getting the Facts Straight)," *Hastings Center Report* 18 (February/March, 1988) 27–32. Also, the President's Report, *Deciding to Forego Life-Sustaining Treatment* 174–81.

⁵ Cranford, "The Persistent Vegetative State" 29.

⁶ *Ibid.* 31.

⁷ *Ibid.* In addition, see the recent "Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient," reprinted in *Medical Ethics Advisor* 4 (August 1988) 111–13.

all else, no matter how good or valuable, must take second place. Though heresy trials are one, perhaps unfortunate, example of this priority, we also have the celebrated examples of martyrdom and individual self-sacrifice.

This perspective reminds us, particularly in the health-care context, that while preserving life is a good—and even a great good—biological life is neither the highest value nor a value that holds ultimate claim on us. To make biological life the ultimate value is to forget our real priorities and to create an idol by making a lesser good our ultimate reality.

The Quality of Life

The meaning and validity of quality-of-life judgments have been debated in the literature for quite some time.⁸ One example in recent decades is Joseph Fletcher's criteria of humanhood.⁹ Although his criteria establish standards for being human, they also implicitly argued that life without a certain level of rationality was not human and consequently not worth living. Most recently Robert Jay Lifton's examination of Nazi doctors emphasized the role of the concept of *lebenunwertes Leben*: life unworthy of life.¹⁰ Such unworthiness consisted primarily in being Jewish, but also extended to mental illness and retardation, as well as to severe physical handicaps.¹¹

Quality-of-life judgments can serve as a code for a life judged to be

⁸ E.g., see George J. Annas, "Quality of Life in the Courts: Earle Spring in Fantasyland," *Hastings Center Report* 10 (August 1980) 9–10; Daniel Callahan, *Setting Limits* (New York: Simon & Schuster, 1987) 187–93; John R. Connery, S.J., "Quality of Life," *Linacre Quarterly* 53 (February 1986) 26–33; Brian V. Johnstone, C.S.S.R., "The Sanctity of Life, the Quality of Life and the New 'Baby Doe' Law," *ibid.* 52 (August 1985) 258–70; Edward W. Keyserlingk, *Sanctity of Life or Quality of Life in the Context of Ethics, Medicine and Law* [a study written for the Law Reform Commission of Canada] (Ottawa: Minister of Supply and Services Canada, 1979) 49–72, 75–105, 185–90; Richard A. McCormick, S.J., "A Proposal for 'Quality of Life' Criteria for Sustaining Life," *Hospital Progress* 59 (1975) 76–79; *idem*, "The Quality of Life, the Sanctity of Life," *Hastings Center Report* 8 (February 1978) 30–36; Warren T. Reich, "Quality of Life," in *Encyclopedia of Bioethics* 2 (New York: Free Press, 1978) 829–40; *idem*, "Quality of Life and Defective Newborn Children: An Ethical Analysis," in *Decision Making and the Defective Newborn: Proceedings of a Conference on Spina Bifida and Ethics*, ed. Chester A. Swinyard (Springfield, Ill.: Charles C. Thomas, 1978) 489–511.

⁹ Joseph Fletcher, "Indicators of Humanhood: A Tentative Profile of Man," *Hastings Center Report* 2 (November 1972) 1–4.

¹⁰ Robert Jay Lifton, *The Nazi Doctors: Medical Killing and the Psychology of Genocide* (New York: Basic Books, 1986) 21.

¹¹ For an interesting contrast between the Nazi interpretation of "quality of life" and what contemporary authors tend to mean by this criterion, see Cynthia B. Cohen, "'Quality of Life' and the Analogy with the Nazis," *Journal of Medicine and Philosophy* 8 (1983) 113–35.

worthless or useless. This orientation comes partially from our consumerist society, in which quality is linked with individuals' norms of excellence and is limited only by the horizons of their imagination and desires.¹² This perspective realizes one's worst fears about quality-of-life judgments, because the removal of any transcendent significance or value to human lives gives the state, institutions, or individuals final control over a person's fate.

The two most crucial levels in the quality-of-life debate are the evaluative and the normative. At the evaluative level three points need to be made. First, it is necessary to distinguish clearly and consistently between physical or biological life and personal life (personhood). When this important distinction is not made, quality-of-life judgments can equivocate between the value of biological life and the value of personhood.¹³ This possibility must be removed. Second, physical life is indeed a value that is not conditioned on any property or characteristic of the person. Here we disagree with Documents F and G, which appear to imply such a conditional value of physical life, e.g. its rationality.¹⁴ In our view physical life is a *bonum onticum*, a true and real value, though created and therefore limited. By arguing that physical life as such is a *bonum onticum* and not a conditional value, i.e. a *bonum utile*, we can affirm that all physical lives are of equal ontic value and that all persons are of equal moral worth. Third, the issue of the evaluative status of physical life may be misplaced from the start. The word "quality" does not and should not refer to a property or attribute of *life*. Rather, the quality that is at issue is the quality of the *relationship* which exists between the

¹² Albert R. Jonsen, "Purposefulness in Human Life," *Western Journal of Medicine* 125 (July 1976) 5.

¹³ E.g., Warren Reich's theological position grounds both the value and the equality of "human life" in the belief that "all men are created as persons in the image of God" ("Quality of Life and Defective Newborn Children" 504). His use of the phrase "human life" is ambiguous here and therefore misleading. The context of his argument is a critique of what he believes to be Richard A. McCormick's position on the value of *physical life*, yet Reich completes his argument by referring to *persons* and their nature and value as images of God.

¹⁴ In fact, several contemporary Catholics have given the impression that the value of physical life is dependent on some inherent property or attribute which, when present, gives physical life its value. It is possible that this way of phrasing the value of physical life is due to the lack of a terminology in the contemporary discussion that can mediate between the two traditional categories of value, viz. *bonum honestum* and *bonum utile*. E.g., see Kevin D. O'Rourke, O.P., and Dennis Brodeur, *Medical Ethics: Common Ground for Understanding* (St. Louis: Catholic Health Association of the U.S., 1986) 213; Richard A. McCormick, *How Brave a New World? Dilemmas in Bioethics* (Washington, D.C.: Georgetown University, 1981) 405-7; David Thomasma et al., "Continuance of Nutritional Care in the Terminally Ill Patient," *Critical Care Clinics* 2 (January 1986) 66.

medical condition of the patient, on the one hand, and the patient's ability to pursue life's goals and purposes, understood as the values that transcend physical life, on the other.¹⁵ We maintain that this reconceptualization of quality-of-life judgments is entirely congruent with the substance of the Catholic tradition.

Normatively, those who oppose quality-of-life judgments fear that life-and-death decisions will be made solely on the presence or absence of certain qualities or properties that a patient's life possesses. This erodes our duties to protect innocent lives, especially of those most vulnerable in our society.

If one contends that our duties to preserve life are based on a prior judgment of whether a specific quality or property of physical life will result in benefits or good consequences to the patient (personal consequentialism) or to society (social consequentialism), then in our judgment those duties to preserve life are improperly grounded in what the patient earns through social accomplishments or potentialities that his/her life might possess. We reject such a normative position because it denies, at least implicitly, the equal ontic value of all physical lives.

We argue that one derives the *prima-facie* duty to preserve physical life from the ontic value of life and the actual moral obligation to preserve life from a teleological, but not consequentialist, assessment of the relationship between the patient's overall condition and his/her ability to pursue life's goals and purposes. The structure of the actual moral obligation is teleological in that the patient's condition is always viewed in relation to the pursuit of life's purposes, and the grounding of the obligation always involves an evaluative assessment of the qualitative relation which exists between these two components. Because physical life is not an absolute value, even those arguing for the sanctity-of-life position recognize definite limits to the obligation to support life.¹⁶ We should not reject quality-of-life judgments, but we should rightly reject any normative derivation of our moral duties from the presence of certain properties of physical or personal life.

Quality-of-life judgments, which are judgments strictly circumscribed by an assessment of the benefits and burdens of medical treatment considered in itself and/or of those benefits and burdens that will accrue to the patient as a result of treatment, function appropriately as ways of

¹⁵ See James J. Walter, "The Meaning and Validity of Quality of Life Judgments in Contemporary Roman Catholic Medical Ethics," *Louvain Studies* 13 (fall 1988) 195-208, esp. 201.

¹⁶ E.g., see John R. Connery, S.J., "Prolonging Life: The Duty and Its Limits," *Linacre Quarterly* 47 (May 1980) 151-65; Johnstone, "The Sanctity of Life, the Quality of Life," esp. 265-69; Reich, "Quality of Life and Defective Newborn Children," esp. 505-9.

qualifying our duties to preserve life. Thus, as long as the value of both physical life and personhood is assured at the evaluative and normative levels, we not only support the role of quality-of-life judgments in medicine but also judge them to be indispensable in proper decision-making. In our view, then, quality-of-life judgments properly supplement and enhance the Christian emphasis on the sanctity of life.¹⁷

The Technological Imperative

We cannot discuss this debate without including a reference to the technological imperative—"if we can do it, we should (or must) do it"—which infers a moral obligation either from a capacity or from the mere existence of a technology.

In the context of high-tech medicine, such an imperative, even if not explicitly subscribed to, is difficult to resist. The same is true even for low-tech or simple technologies. Some medical technologies that administer nutrition and hydration are relatively simple, e.g. parenteral methods of delivering nutrients. Other methods are more invasive, e.g. gastrostomy tubes, and they carry with them potential iatrogenic dangers, such as infection resulting from the surgical creation of the stoma. Yet they are much less invasive than other procedures and are more risk-free if properly cared for. Furthermore, their use provides a clear and demonstrable benefit: the prolongation of physical life. Indeed, feeding tubes may be unique among all medical technologies in that they almost exceptionlessly deliver on their claims. The technological imperative is augmented by simplicity and predictability of outcome and consequently presents an apparently unassailable case for use. But this very simplicity, ease of use, and ready availability disguises the moral dimension of the technology's use.

One must consider the use with respect to outcome. The outcome, of course, is the preservation of physical life. *Prima facie* such an outcome is valuable, but it must be considered with respect to other values and/or goods, for physical life is not the only or absolute good. Thus other goods, such as human dignity, ought to be considered. Our point is that, in and of itself, the presence of a technology and the capacity to utilize it constitute at most a *prima-facie* case for its use. One cannot automatically or necessarily infer an actual moral obligation from the mere existence or presence of a technology.¹⁸

¹⁷ Keyserlingk also argues a similar position in his report for the Law Reform Commission of Canada. See his *Sanctity of Life or Quality of Life*, esp. 49-72.

¹⁸ We agree with the report from the Hastings Center that "All invasive procedures for supplying nutrition and hydration—all enteral and parenteral techniques—should be considered procedures that require the patient's or surrogate's consent . . ." (*Guidelines on the Termination of Life-Sustaining Treatment* 61).

The Ordinary/Extraordinary Means Distinction

This well-used distinction can be dated as early as the 17th century and has been used by popes and theologians in arguments to determine one's moral obligation to preserve human life.¹⁹ Some maintain that the key element in the traditional use of the distinction is the *classification* of technologies, medicines, or procedures. Consequently they are considered apart from the patient on whom they are used. Once classified, the moral question is then essentially resolved. In the feeding-tube example, the late John Connery, S.J., argued that since nutrition and hydration kept individuals alive, the technology fitted the classic definition of ordinary treatment and therefore was morally mandatory.²⁰

If one shifts the perspective from an abstract classification of technologies to a *patient-centered* approach²¹ which gives moral weight to the autonomy of the patient and looks to the impact of these technologies on the patient's medical and nonmedical condition as a whole, one can establish a different moral argument. Here the expressed wishes of the patient have a legitimate moral claim based on our valuing the dignity of the individual and on our respecting the sacredness of his or her conscience. Second, it is the proportionality or disproportionality of benefits and burdens *to the patient* that makes any medical treatment or procedure, including the medical provision of nutrition and hydration, obligatory or optional. Because the technology can neither ameliorate a PVS patient's general clinical condition nor restore this individual to any state of health where the patient might pursue the values of life, the means are extraordinary and not morally required. Therefore ordinary and extraordinary are determined not by classifying the technology but by considering its impact on the patient and his/her overall condition. Additionally, and following directly from the above, the distinction must adopt a patient-centered perspective to avoid the technological imperative.

The Burdensomeness of Life

The specific issue here is whether the burdensomeness of the life preserved by the offering of nutrition/hydration can or should be part of

¹⁹ See Gerald Kelly, S.J., *Medico-Moral Problems* (St. Louis: Catholic Hospital Association, 1958) 128–41.

²⁰ John R. Connery, S.J., "The Clarence Herbert Case: Was Withdrawal of Treatment Justified?" *Hospital Progress* 65 (February 1984) 32–35 and 70.

²¹ Recently several authors have argued for a patient-centered approach in clinical decision-making: e.g., see Robert M. Veatch, *Death, Dying, and the Biological Revolution: Our Last Quest for Responsibility* (New Haven: Yale University, 1976); James J. Walter, "Food & Water: An Ethical Burden," *Commonweal* 113 (Nov. 21, 1986) 616–19.

the overall assessment of burden in the determination of ordinary/extraordinary as we have just outlined it. Considered only in itself, the medical provision of nutrition and hydration would most often be considered ordinary. Thus for some people any considerations beyond the technology itself would lead to an improper questioning of the value of the patient's life.

We think the concepts of burden and quality of life should be linked. Burden can accrue to the patient precisely through the administration of modern technology and can be a consequence of a life lived merely at the biological level with no hope of restoration or further pursuit of temporal or even eternal goals. In this sense the burden is iatrogenic. For the PVS patient, medicine has reached its limit in bringing this individual to any level of health and wholeness. Again, this patient-centered approach focuses on the conditions under which this valued life is to be lived and seeks to identify what interests of the patient can be achieved. Thus we argue that burden is to be assessed not only from the perspective of the burdensome effects of the technology itself but, like Document C, also from the perspective "of the burdens that an individual experiences in pursuing the goals or ends of life" as a result of the intervention of the medical technology. Although it is doubtful that the PVS patient would experience this burden personally, the burden is real, even if experienced secondhand by the family and/or by those professionals who must care for the patient.²²

Fear of Being Trapped

The expected benefit of tube feeding is the preservation of life post-trauma or posttreatment so that other important work can go on, e.g. treatment or diagnosis. But there comes a time—sometimes sooner, sometimes later—when one knows that all has been tried and cure is not possible. What was formerly appropriate to do, viz. trying to cure, is now inappropriate, and our efforts must shift to accompanying the patient on his/her final journey.

We agree with Document F that it is precisely here that a family may

²² Though we have refrained from making any judgment about the financial burden either on society or on insurance companies in providing funds for PVS patients, the fact that there are approximately 10,000 of these patients in the U.S. strongly inclines us to agree with Daniel Callahan that "It is hard to see how a debate on that reimbursement issue can be forestalled much longer." See Callahan's "Vital Distinction, Mortal Questions: Debating Euthanasia & Health-Care Costs," *Commonweal* 115 (July 15, 1988) 404. It is important to note here that the *Declaration on Euthanasia* and Document E, both following Pius XII, do permit one to assess the burden on the family or on the community in judging whether a treatment is disproportionate. See the *Declaration on Euthanasia* in *Origins* 10 (Aug. 10, 1980) 16.

feel or actually be trapped. Having appropriately initiated medical feeding to preserve life while other tests, procedures, and medications were tried, the family may now be frustrated in its desire to remove the feeding tube. Though such feeding only preserves biological life, attempts to withdraw the feeding may be challenged by medical personnel or by others.

Our fear is that individuals or families may inappropriately refuse to initiate medical procedures for delivering nutrients because of the fear of not being able to withdraw these procedures when that becomes appropriate. Thus individuals who may genuinely benefit from this type of procedure could be deprived of its goods. Such a situation would be tragic beyond belief. But because of the technological imperative, our near absolutizing of biological life, and the fear of taking personal responsibility in medical decision-making, this outcome is almost guaranteed. However, recognizing patient autonomy and shifting to a patient-centered calculation of benefits and burdens in the fashion we have described will counter this unfortunate situation.

Summary

In our judgment, the cumulative effect of our arguments supports the legitimate forgoing or withdrawing of nutrition and hydration to PVS patients. This judgment can properly be reached without supporting any efforts or claims for euthanasia and without making any improper judgments about the worth of a particular life. After carefully considering both the patient's known wishes and the qualitative relation between the patient's medical condition and the pursuit of life's purposes, one may appropriately judge that such a therapy is disproportionate and morally optional. This conclusion seems to be very close to, if not the same as, the judgment contained in Document E.

SUGGESTIONS FOR FUTURE DISCUSSION

Having reviewed the results of the survey, the points raised in the various documents submitted to us, and identified several ethical arguments supporting the removal of medical feeding tubes, we wish to make some suggestions for the future conduct of this debate.

Nomenclature

Here three issues. First, the misuse of "euthanasia" in the debate. In our survey, ordinaries were asked whether the diocesan committee considered the removal of feeding tubes from PVS patients to be an act of involuntary euthanasia. The responses are very interesting. Most answered that they considered the withdrawal of these tubes to be "passive or indirect and therefore permitted." A significant number responded

that "it depends," and only four respondents answered that this action was "active or direct and therefore forbidden."

The response from the research center, Document D, states that the withdrawal of feeding tubes from PVS patients, except in very limited cases, is an act of "euthanasia by omission," and in most cases anyone who does this has the moral intention to end a life which is considered valueless or excessively burdensome. Two assumptions, frequently cited among those who consider such actions as euthanasia, seem to underlie this conclusion. The first is that the medical provision of nutrients offers a benefit by preserving the life of the patient. The second is that this nourishment should be considered as ordinary *care*, similar to all other types of care.

The moral characterization of the intention of the one authorizing withdrawal as "ending a life" forces this discussion into the context of euthanasia. In its brief to the New Jersey Supreme Court on the Nancy Ellen Jobs case, the New Jersey Catholic Conference argued that the withdrawal of feeding tubes is "intentional euthanasia."²³ Because we disagree both with the two basic assumptions which underlie this argument and with the description of the moral intention of these acts of withdrawal as killing, we argue that the use of the term "euthanasia" should be avoided in the debate.

A moral analysis of euthanasia necessarily involves an assessment of the intention. Though they may be motivated by humane reasons, morally all acts of euthanasia intend the death of the patient either by commission or by omission, and thus by definition these acts constitute the unjustified killing of a patient. However, we argue that in withdrawing nutrition and hydration the intent is either to end a procedure that no longer benefits the patient or to prevent the person from being entrapped in technology. The patient's death, while foreseen, results from the justified discontinuance of a technology that itself can neither correct the underlying fatal pathology, i.e. the permanent inability to ingest food and fluids orally, nor offer the patient any reasonable hope for what we have defined as quality of life. In our judgment, then, it is inappropriate to characterize the withdrawal of medical nutrition and hydration from PVS patients as euthanasia.

Second, we suggest that in future discussion of this issue the word

²³ New Jersey State Catholic Conference Brief, "Providing Food and Fluids to Severely Brain Damaged Patients," in *Origins* 16 (Jan. 22, 1987) 583. The Conference was following the Lutheran theologian Gilbert Meilaender in his "On Removing Food and Water: Against the Stream," *Hastings Center Report* 14 (December 1984) 11-13. An opposing position was taken by Bishop Louis Gelineau of Providence, R.I., in the Marcia Gray court case. See his statement in *Origins* 17 (Jan. 21, 1988) 546-57.

"forgo" should be used rather than "withhold." The reason is that "withhold" connotes that something is denied to someone who has some entitlement to it. When family members appropriately decide that a medical treatment will not truly benefit the PVS patient, their decision is to refrain from pursuing what is not useful to the loved one, not to deny something for which the patient has a need or a right. Our intent is twofold: to avoid a begging of the question and to suggest a terminology which allows the argument to come forward and be evaluated on its own merits. The terminology of forgoing and withdrawing, we think, will prevent the argument from becoming confused linguistically and prejudged methodologically.

Third, how describe *nutrition and hydration*? What to call the nourishment administered to a patient introduces a variety of problems, descriptive as well as symbolic. The terms "food and water" conjure up, among other things, a variety of images depending on taste and ethnic background. They also connote a meal in which one actively participates or, if with others, shares. The symbolism associated with food and water is deep, and rightly so. For they symbolize membership and participation in a community, and to deny these common but significant realities to someone is more than depriving that individual of nourishment; it is cutting him/her off from the community.

The symbolic level of food and water is what inclines several individuals to argue against the removal of nourishment from the PVS patient.²⁴ The forgoing or the removal of nutrition says that the individual has been marked and put outside the community, outside society. This further signifies the valuelessness of the person and his/her uselessness to the community. Therefore one must continue to provide this nourishment precisely as a symbol of inclusion.

However, one must also recognize the limits of this symbolism, particularly in the case of PVS patients. To begin with, we have a situation in which the patient is fed and does not eat; the experience is entirely passive. Orderlies or nurses do not deny trays of food to patients nor do they forcibly remove these from the hands of patients. Nutrition and hydration are administered to the patient and the body absorbs them; the feeding process is completely involuntary. Second, the symbolism of the meal is utterly absent, even if others are there. There is no meal, only a medical feeding. Though nourishing, it is difficult to consider such a liquid protein diet as food. For food, in addition to having a certain biological reality, is also a human construct and is more than the sum of its nutritional value. It is the color, texture, aroma, taste, and company

²⁴ E.g., see Daniel Callahan, "On Feeding the Dying," *Hastings Center Report* 13 (October 1983) 22.

in which it is shared. For the PVS patient, all of this is absent. To call this nourishment food is to invest it with more meaning than the reality of the situation can bear.

Also, these patients do not consciously hunger or thirst. But even if these states were experienced, medical procedures for supplying nutrition and hydration might not relieve the feelings.²⁵ "Medical nutrition and hydration" seems an appropriate phrase for this form of nourishment, because it captures in a nonjudgmental fashion the medical provision of the nourishment as well as the passivity of the experience. The patient is fed and consequently the body is nourished, but he/she certainly does not participate in a meal and clearly does not share table fellowship. This terminology also describes the procedure without begging the moral question of whether one ought to provide it, and it avoids the intrusion of inappropriate symbolism. This terminology will keep us from making more of the situation than is there, but it will also keep us from making less of it.

Ordinary and Extraordinary Treatment

Here three considerations. First, as noted above, there is a difference in how these traditional terms can be used. For some, the terms are the basis on which the procedure or technology is classified. Once classified, the correct action is relatively clear. If ordinary, the procedure or technology is morally obligatory; if extraordinary, it is morally optional. This schema encounters significant problems when the pace of technological change increases. In addition, the term "ordinary" in its moral or normative sense has been used to declare a certain technology routine or customary in a medical or descriptive sense. The descriptive use of "ordinary" generally refers to what is usually done, but this involves little or no moral analysis of what ought to be done.

These equivocations have precipitated a rethinking of the terminology that now aims at the evaluation of the benefit-burden ratio for the patient.²⁶ Consequently a procedure is judged ordinary in a normative sense if its effects on the patient provide proportionately more benefits than burdens. On the other hand, a treatment is extraordinary in a moral sense if the evaluation produces the contrary conclusion. Thus these terms are now seen as the conclusion of a process of evaluation rather than as a classification of a procedure. It is not unusual that a Jehovah's Witness would judge a clinically routine blood transfusion morally extraordinary because of the disproportionate consequences for his or her

²⁵ Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment* 59.

²⁶ See the *Declaration on Euthanasia*, where the terminology has shifted to a discussion of proportionality between the benefits and the burdens.

eternal salvation. Similarly, a person on long-term dialysis might conclude in some circumstances that use of this technology is extraordinary because of its impact on diet and life style.

Understanding ordinary and extraordinary as conclusions of an evaluative process rather than as a classification schema permits a much more appropriate use of the terms in the practice of contemporary medicine. Furthermore, the danger of equivocation is now removed and the meaning of the terms is moral, not descriptive.

Second, autonomy. Though the concept has undergone some criticism in the last few years because it has been taken to an extreme by functioning independently of or to the exclusion of other values, nonetheless we might do well to remember the old adage that abuse does not take away use. Autonomy is an important value, and the proper starting point for these discussions is the expressed wishes of the competent patient. To begin at this point is to respect the dignity of patients and their conscientious decisions. Statements that individuals make about their death or the circumstances of their dying are extremely important. Minimally, they form the foundation of any and all discussions about the initiation or withdrawal of therapy. These statements, which need to be discussed and evaluated in light of the clinical situation and other relevant moral values, always constitute a core element in the final decision about treatment.

Third, quality-of-life considerations and the goal of medicine. As we have noted, quality-of-life judgments should not be construed as judgments about the worth of either physical or personal life. They are not concerned with assessing qualities or properties that, when present, make life itself valuable. Rather, these judgments are evaluative and normative claims or assessments about the relation between the patient's overall condition and his/her ability to pursue material, moral, and spiritual values which transcend physical life but do not give that life its very meaning and worth. Consequently quality-of-life judgments help specify concretely the meaning of the terms "benefits," "burdens," and "best interests" of a patient, as well as the limits of medical interventions within a given historical and cultural situation.

Whereas all physical life is of equal ontic worth and all personal life is of equal moral value, the quality of the relation between these lives and the pursuit of values is not equal. Due to multiple factors, some of which have to do with individual genetic endowment and the ways in which we live our lives and some of which are dependent on the nurturing and accessibility of values in a given culture, a large portion of the population is fortunate enough to attain a high quality of life. Other individuals, regrettably, are not as fortunate, and they must live most of their lives

pursuing life's purposes at a less than optimal level. But some have no discernible or such a minimal qualitative relation between their overall condition and the pursuit of values that we would argue that those in this last category have no moral obligation to prolong their physical lives. In these cases all treatment can be withdrawn from them. Not long ago all PVS patients' lives would have been mercifully ended by their inability to ingest food orally, but the intervention of modern technology today has not been as merciful.

No doubt, one of the principal factors that has provoked this debate has been the ambiguity about the central goal of medicine itself. Medicine rightfully seeks to prevent death, especially an untimely death, to alleviate pain and physical suffering, and to promote health as far as possible. Indeed, these are important goals. However, we argue that all these goals are really subordinate to the more encompassing goal of serving the purposefulness of personal existence.²⁷ In other words, the central and overarching goal of clinical medicine is to enhance the qualitative relation between the patient's condition and the pursuit of life's goods. Thus, other things being equal, when medicine can intervene to ameliorate the quality of the relation between the patient's condition and the pursuit of life's goals, then such an intervention can be considered a benefit to the patient and is in his/her best interests. On the other hand, because of the overall condition of the patient, when a proposed intervention cannot offer the patient any reasonable hope of pursuing life's purposes at all or can only offer the patient a condition where the pursuit of life's purposes will be filled with profound frustration or with utter neglect of these purposes because of the energy needed merely to sustain physical life, then any medical intervention (1) can only offer burden to the life treated, (2) is contrary to the best interests of the patient, (3) can cause iatrogenic harm or the risk of such harm, and (4) has reached its limit based on medicine's own principal reason for existence, and thus treatment should not be given except to palliate or to comfort.²⁸

Responsibility in Decision-Making

When the biotechnological revolution began in earnest and humans discovered new powers and capacities, one of the first slogans to describe this new state of affairs was "playing God." This phrase denoted the power humans now wielded over previously untamed and uncontrolled natural realities. But we detect a shift emerging. Rather than humans "playing God," it is now technology that is "playing God." Our machines seem to have developed a life and power of their own. How, for example,

²⁷ Jonsen, "Purposefulness in Human Life" 6.

²⁸ Walter, "The Meaning and Validity of Quality of Life Judgments" 207.

does someone with an artificial heart die? How does someone on a respirator stop breathing? How does someone with a feeding tube refuse to be nourished? Very often, once in place, there seems to be no way, short of a cosmic power failure, to end the domination of the machine. We are, clearly, much better about removing machines now than we were initially, but many are still very reluctant to intervene in the activities of the machinery. Often enough, court intervention is the only recourse the family or guardian has to stop a machine.²⁹

Have we surrendered our decision-making powers to machines? Do they "play God" by exercising their untiring, endless vigilance over us and our loved ones? We have not improved our situation much if indeed we have turned our appropriate decision-making responsibilities over to machines. Although such decisions are dangerous and difficult at times, humans have a legitimate level of responsibility for deciding about the forgoing or withdrawing of treatment. Surrendering that responsibility because a machine is in place is truly the worship of a false god.

The family typically plays an important role in these decisions, because often the individual most affected by a decision cannot participate directly. Such involvement is proper, because generally the family has a relationship with the patient and knows his/her wishes. The family is normally in the best position to discern the patient's wishes or desires. Thus it can either relate what the patient actually wanted or, failing that, relate its best judgment of what the patient would have wanted. If the family has no direct knowledge of the patient's wishes, it is still the appropriate decision-maker. The family has a socially recognized relation to the patient and can be presumed to have the best interests of the patient in mind.

Should conflicts arise which simply cannot be resolved at the local level with the assistance of the physicians, an ethics committee, a patient's rights advocate, the clergy, or other resources, then—and only then in our judgment—is it appropriate to think of turning to the courts for a resolution of the issue.

CONCLUSION

On both practical and theoretical levels, the question of forgoing or withdrawing medical nutrition and hydration from PVS patients appears to have reached no clear consensus inside or outside the Catholic community, although our sense is that many, if not most, people are uncomfortable with continuing this technology when there is no reasonable hope of an improvement in the patient's prognosis. This is not to say

²⁹ There have been several court cases recently involving patients in a persistent vegetative state. Two of the more notable cases are Paul Brophy and Nancy Ellen Jobes.

that there is an atmosphere of joy about the situation or a zeal to begin a withdrawal procedure. Rather, there is a sense of reluctance, a very great sense of caution and care, and a most careful focusing on the moral arguments.

Finally, we wish to highlight two aspects of the debate that we think are particularly crucial. First, the moral intention to forgo or withdraw medical nutrition and hydration is not identical with the intention in euthanasia. This conclusion is confirmed by our own work and in most of the literature. People who advocate the forgoing or the withdrawal of feeding-tubes are not advocating any kind of euthanasia policy. The clear intent is to end a procedure that is not proportionately benefiting the person or to release the person from entrapment in technology. Thus, while forgoing or withdrawing feeding tubes is not "medical killing," maintaining them may well produce "involuntary medical living." Second, forgoing or withdrawing this technology is argued as a moral option, not as a mandatory practice. Therefore the conclusion we share with most authors is either that forgoing or withdrawal is not prohibited or it is within the permitted range of moral activities. We also agree with Document E that individuals who conclude that such a practice is morally appropriate should not be prohibited from acting on that conclusion.

We expect that the debate will continue and that different aspects of it will be further examined. Our hope is that this report and presentation of an argument will help structure that process and assist in its resolution.³⁰

³⁰ Support for the survey was provided by the Research Development Council of Worcester Polytechnic Institute, and the authors acknowledge their gratitude for this assistance.