Persistent Unconsciousness and the Use of Assisted Nutrition and Hydration

Medical and Moral Reflections*

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Abstract

The subject of this article is the medical condition popularly known as the persistent vegetative state or PVS. Because, as many have noted, including Pope John Paul II in 2004, the term “vegetative” carries with it such pejorative connotations, I will try to avoid using it as much as possible and will substitute the term “persistent unconsciousness” in place of it. I have divided the subject into two main sections, the medical and the moral, with several smaller divisions in between. My intended purpose in this article is two-fold. First, it will clarify several major lacunae in the popular knowledge of persistent unconsciousness itself, and second, it will examine some recent developments in the Church’s moral teaching regarding the care of such patients. It is my hope that this approach will help to shed some light on the common misconceptions regarding persistent unconsciousness and to clearly present the Church’s moral tradition as it serves to address the needs of these individuals.

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Medical Considerations

Introduction

Currently, Americans are more than three decades removed from the first nationally known case of persistent unconsciousness. The most recent case to garner wide attention involved Terri Schiavo, a young married woman, who suffered an inexplicable collapse in 1990 and lived in a seriously debilitated condition until the removal of the food and fluids sustaining her life caused her death in March 2005. The most significant of all the cases in America concerned a young Missouri woman named Nancy Beth Cruzan.¹ Critically injured as a result of a 1983 automobile accident, Nancy lived in a state of persistent unconsciousness for seven years until the assisted food and fluids sustaining her life were removed at the request of her parents. What makes this case so important is not so much the immediate legal ruling: by a five to four margin the U.S. Supreme Court decided in favor of the state of Missouri, which required that before Nancy Cruzan's life-sustaining food and fluids were removed, clear and convincing evidence be provided to show that such was her desire. Instead, the lasting impact of the *Cruzan* case rested on three factors: 1) it was a precedent setting end-of-life cases on a national stage (it was the first instance in which the U.S. Supreme Court had heard an end-of-life/right-to-die case); 2) it formally recognized living wills and durable powers of attorney for health care as evidence of the health-care wishes of an individual patient; and 3) it formally recognized assisted nutrition and hydration as a medical treatment and not an aspect of basic nursing care. Finally, the case that started it all centered on a twenty-one-year-old New Jersey woman named Karen Ann Quinlan. Karen suffered anoxia (loss of oxygen to the brain) as a result of an accidental overdose of diazepam and alcohol. Back in 1975 the legal battle surrounding her did not stem from a decision to provide or withdraw nutrition and hydration, but the decision to provide or withdraw the artificial ventilation sustaining her life.

Since the aftermath of the *Quinlan* case, experts in medicine, law, and theology have wrestled with the questions that arose from the condition of persistent unconsciousness. Among them are the following: What exactly is the physical condition of a patient with persistent unconsciousness? How can an accurate diagnosis be made? What level of care should persons suffering from persistent unconsciousness receive? What are the limits (if any) of the care owed to such patients? Over the ensuing decades various medical responses were given to these questions. The most significant of which was the 1994 Multi-Society Task Force document, "Medical Aspects of the Persistent Vegetative State,"² published by five societies of the American medical community (American Academy of Neurology, American Association of Neurological Surgeons, American Neurological Association, Child Neurology Society, and the American Academy of Pediatrics). Whether or not it

was intended to, the Multi-Society Task Force document ultimately constituted the definitive word of the medical community regarding the condition and care owed to such patients. Coupled with the U.S. Supreme Court ruling in the *Cruzan* case, it significantly reduced any further medical or legal debate on the PVS as an ethical issue that demanded further consideration.

Persistent Unconsciousness

In order to justly consider the moral implications of the decision to provide or withhold or withdraw food and fluids from incompetent patients like those suffering from persistent unconsciousness, it is beneficial to take a closer look at its characteristics and its causes. First of all, what exactly is the persistent vegetative state? In 1994 the Multi-Society Task Force defined the PVS as “a clinical condition of complete unawareness of the self and the environment accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brain-stem autonomic functions.”³ In other words, a diagnosis of PVS means that, despite periodically having their eyes open and appearing to be conscious, patients living in a condition of persistent unconsciousness are totally unaware of themselves or their surroundings. That the body remains alive (heartbeat, respiration, digestion, etc. remains active) is due to the preservation of all or part of the functions of one’s hypothalamus and brain stem.

Persistent unconsciousness is characterized by a patient’s “eyes-open” state of apparent unawareness, which separates it from coma, which is a condition of “eyes-closed” unawareness. Comas, likewise, are transitory conditions normally lasting no more than one month, while persistent unconsciousness can last indefinitely. Normally, patients suffering a state of eyes-closed coma either die from their injuries, recover consciousness, or enter an eyes-open condition of persistent unconsciousness. Thus not infrequently heard reports of a person suffering from “irreversible coma” or recovering after years and years in a “coma” are likely inaccurate. Instances of comatose patients remaining in such a condition for longer than a month are rare.⁴ The Multi-Society Task Force document reported that individuals in the PVS retain the ability to blink and move their eyes across a room. They retain some ability to move; they shed tears, make noises, and exhibit apparent emotional responses. That being said, however, any motor activity, noises, expressions, or other capacities exhibited by patients in a state of persistent unconsciousness are considered by authoritative medical opinion to be mere reflex actions without purpose or intent.

On the other hand, this assertion is not a universal opinion. There is a great deal about brain injury in general and persistent unconsciousness in particular that currently lies outside the boundaries of medical knowledge. A good example of the limits of medical science involving the brain can be found in the opposing opinions of the doctors who

examined Terri Schiavo in 2002 (several years before her death). After their examinations were concluded, one group of physicians reported their certain diagnosis that Terri was at least minimally conscious, while the other group emphatically insisted that she was definitely in the PVS.⁵ To illustrate the difficulty in this regard, an account from David Gibbs, a lawyer retained by Terri's parents Bob and Mary Schindler, is helpful. He recalled,

Interestingly, Terri responded very differently to her dad. Bob had developed this playful routine he'd go through with her each time they were together. I watched Bob announce, "Here comes the hug" as he wrapped her in a bearlike embrace. Then Bob said, "You know what's coming next—the kiss!" He then moved in close for a smooch. Keep in mind that Bob sports a scratchy mustache. His chin was often unshaved too, which caused his facial hair to tickle Terri's face. Over the years, as she did during our visit, Terri would scrunch up her whole face in preparation for the assault on her cheeks that she knew was coming with Bob's scratchy kiss. Her family called this Terri's "lemon face." With a giggle, she'd turn her head away as if toying with her dad. In the end she'd laugh as his lips made contact with her cheek. She responded the exact same way every time to her father's auditory cues as he consistently initiated this playful routine.⁶

While in no way does this single account constitute evidence solid enough to overthrow years of established medical opinion, Mr. Gibbs's description of Terri Schiavo's response to auditory cues, coupled with reports of a similar nature from other diagnosed PVS patients, does raise questions about the diagnosis of PVS in general and the capacities or non-capacities of patients with persistent unconsciousness.

Misperceptions and Misinterpretations of Persistent Unconsciousness

According to the Multi-Society Task Force document, approximately 10,000 to 25,000 adults are believed to live in the PVS in the United States each year, not including four thousand children.⁷ While at first glance this number seems inordinately large, several other factors need to be taken into consideration before a complete picture of the PVS can be accurately perceived. Fifty percent of such patients have been unconscious for less than six months—70 percent for less than one year. Thus only 30 percent of the total, roughly 3,300 to 8,300 patients, have been unconscious for more than one year.⁸ It is a widely held belief that the persistently unconscious patient lives in this state day after day, month after month, year after year, on and on and on. One of the favorite illustrations used by the late Father Richard McCormick, S.J., to describe the futility of maintaining the lives of such individuals was a scenario of a three-hundred-bed ward filled with unconscious patients whose lives were sustained in this condition for years and years.⁹ The truth of the

matter is considerably different. Analysis of clinical data for mortality shows that 82 percent of persistently unconscious patients die before three years have passed. Ninety-five percent die before five years have passed.¹⁰ Another small percentage of patients will recover consciousness. The likelihood of survival in a condition of persistent unconsciousness beyond fifteen years (as was the case for Terri Schiavo) is one in 15,000 to 75,000.¹¹ Thus unconscious patients like Quinlan, Cruzan, and Schiavo constitute the rarity. We have to remember that the persistently unconscious patient has suffered a severe brain injury, and often times, despite the delivery of food and fluids, the patient will die. The figure of 10,000 to 25,000 adults is a constantly changing, not a static, figure. It is incorrect, therefore, to base treatment decisions on the belief that a diagnosis of PVS automatically means that this person will exist in such a condition indefinitely. The argument to allow the removal of life-sustaining food and fluids from the position of its “interminable” duration is most often a hollow one for the simple reason that the overwhelming majority of such individuals do not live that long.

Another misperception regarding persistent unconsciousness is the commonly expressed sentiment that such individuals suffer a “fate worse than death.” While certainly a condition of great debility, the charge that persistent unconsciousness constitutes a “fate worse than death” is based much more on fear than any true knowledge of the condition. Further, everyone should be able to perceive the inherent bias that underlies such an assertion. It is completely contrary to justice to evaluate the quality of another person’s life, particularly the life of someone living in a debilitated condition, from a perspective of health, ability, and vigor. An important and often overlooked source that should be considered is the assessment of those people who have actually recovered consciousness. In the published accounts of several such persons, for example, Carrie Coons, Sgt. David Mack, and Terry Wallis, none reported that they wanted to die or that they were suffering a “fate worse than death.”¹² It might seem surprising to some, but there are no published reports of patients who have recovered consciousness only to exclaim, “Kill me, kill me, kill me, I might become unconscious again!” “Remove the measures sustaining my life so that I can escape this ‘fate worse than death!’” It appears that assertions about a “fate worse than death” are most often made by healthy individuals who try to imagine what a condition of debility might be like, but who lack a necessary foundation for such a position.

The question of pain and suffering in the PVS has also proven to be problematic. Over the past several decades, three basic arguments have been advanced which use the experience of pain and suffering to justify the removal of food and fluids from persistently unconscious patients. The first argument is based on the definition of the PVS itself, namely that such individuals are completely unaware of themselves or their environment. A representative example of this position comes

from the 1989 statement of the American Academy of Neurology which asserted that persistently unconscious patients were completely unable to experience pain and/or suffering.¹³ From this position it is not a great leap to advocate the removal of sustenance from the persistently unconscious if they are suffering “a fate worse than death,” and they will not experience pain and suffering as a result of the removal. Of course, not all physicians agree with the conclusion of the American Academy of Neurology. A 1996 study of physicians and hospital administrators found that 13 percent of this group believed that persistently unconscious patients retained some level of awareness and 30 percent believed that such patients could experience pain.¹⁴

The second argument contends that, although by definition persistently unconscious patients are completely incapable of experiencing pain and suffering, if they could be aware of their situation they would suffer so greatly that they would desire the removal of the food and fluids sustaining their lives. Speaking about Nancy Cruzan, one physician remarked that,

No matter what the Court says about preservation of life, potential for abuse, and state’s rights, I am convinced that Nancy Cruzan would cry out in horror if she were ever made aware of her mindless dehumanizing existence. She would be even more appalled (as we all would be) if she knew the ordeal her parents have been through trying to do what Nancy would have wanted.¹⁵

So even if pain and suffering is a complete impossibility for the persistently unconscious patient, imagining what they might feel is held up as a justification for the withdrawal of life-sustaining food and fluids to induce death.

The third argument completely bypasses any possible feelings of pain and suffering the patient might experience and instead casts its attention on the deleterious effects that caring for such debilitated patients might have on medical personnel. Using this line of reasoning Dr. Marcia Angell argued,

But what about the reverse situation? Suppose a family wishes to keep a patient who is in a permanent vegetative state alive as long as possible? Do care givers—demoralized by providing limitless, expensive care in a hopeless case—have the right to stop treatment anyway so that the patient will die?¹⁶

In this instance the intent to effect the death of the patient who is persistently unconscious is quite clear: “stop treatment ... so that the patient will die.” For over three decades the mantra of patient self-determination and individual autonomy has been used to advance the patient’s right to accept or refuse the treatments offered by medicine. It would seem, however, that in the case of persistent unconsciousness the only decision desired is the one that would result in the death of a patient whose life has been deemed of insufficient quality to warrant continuance. The request of a patient or his or her surrogate decision maker to

have assisted food and fluids provided in the event of incompetence is, in this circumstance, dismissed because of the “burden” placed on medical professionals.

Care versus Medical Treatment

Before turning to the moral aspects of this topic, two other important medical considerations deserve mention. The first involves the distinction between care and medical treatment. At a time in which something as simple as food commands the name “nutrition” if it passes through a little plastic tube before entering the body, and water bears the name “hydration” for the same reason, it is interesting to note that before 1983 nutrition and hydration were merely food and water and, more importantly, classified as an aspect of basic nursing care.¹⁷ After 1983, once it became clear that, like Karen Quinlan, the lives of unconscious patients could be maintained if they received food and water, a shift took place in medical thought and practice. From this point forward, by medical and legal means, an attempt was made to reclassify the delivery of assisted food and fluids as a medical treatment and no longer an aspect of basic nursing care. The distinction is important. Basic nursing care is something that is normally provided to all patients regardless of their physical condition, e.g., things like good hygiene, a comfortable room temperature, alleviating pressure points, and at one time, food and fluids. Medical treatments, on the other hand, were interventions that could be accepted or refused according to the desires of the patient or surrogate care giver. By 1986 official steps were taken. In its *Current Opinions* publication the Council on Ethical and Judicial Affairs of the American Medical Association unilaterally declared that,

Even if death is not imminent, but a patient’s coma is beyond doubt irreversible ... it is not unethical to discontinue all means of life-prolonging medical treatment. Life-prolonging medical treatment includes medication, and artificially or technologically supplied respiration, nutrition, and hydration.¹⁸

Within a short time this opinion became more and more entrenched so that by 1990 all of the major American medical institutions had followed suit and classified the delivery of food and fluids as a medical treatment.

Taking a brief pause, it is important to ask, “Upon what evidence was this decision based?” According to research, there was no overwhelmingly conclusive aspect of assisted nutrition and hydration (ANH) delivery that absolutely and irrefutably made it a medical treatment. Of course, the placement of a gastrostomy tube required the medical expertise of a physician, but after placement, pretty much anyone could be trained to provide nutrition and hydration through the tube. On the other hand, there are substantial differences that separate the goal or purpose of medical treatments from the goal or purpose of nutrition and hydration. Chief among these differences is the fact that food and fluids

serve only to meet basic bodily needs. Whether you are young, old, sick, healthy, male, or female, food and fluids maintain life. Medical treatments, by contrast, are used to directly effect a cure of a disease or the symptoms of a disease. Food and water have no bearing on the cure of a disease or the symptoms of a disease. Furthermore, we do not eat and drink to cure cancer or other diseases; we do not go to a restaurant to get “medicine.” The only direct purpose of ingesting food and fluids is to maintain life; it does not serve the same purpose as medical treatments.

Certainty of Diagnosis

A second important consideration raises questions regarding the level of certainty expressed by the medical community in the diagnosis of unawareness in a state of persistent unconsciousness. According to the widely accepted definition of the PVS, it is a clinical condition of complete unawareness of the self and the environment. This assertion is based on several factors that range from the observations of the injured patient, to the data from positron emission tomography (PET) scans that gauge cerebral glucose consumption, to the current state of anatomical and physiological knowledge.¹⁹

There is, however, good reason to doubt the widely accepted conclusion of absolute unawareness. A 1997 article written by neurologist D. Alan Shewmon is illustrative here. He wrote about an incident in which he discovered that a medical anomaly—two children born with hydranencephaly—exhibited evidence of conscious awareness. This impossible discovery caused Dr Shewmon to question the accepted medical opinion regarding the condition of persistently unconscious patients. He wrote:

Still, I could not help wondering: if we could all have been wrong about so certain a “fact” in the congenital case, what was the guarantee that we might not also be wrong about the same “fact” in the adult case? What was the empirical evidence that in adults all consciousness resides in the cortex and that without cortex there can be no consciousness of any sort? All major discoveries in medicine—such as the circulation of blood, the germ theory of infectious diseases, ... etc., ... can be traced back to some seminal case, experiment, or observation. I therefore went to the literature on coma and PVS, expecting to trace the bibliographical tree back to its historical trunk, i.e., a key article or set of articles definitively establishing the cortical basis of consciousness. Surprisingly, I soon realized that I was on a wild goose chase. No such case, study, or article existed. Rather, a variety of speculations on the neuroanatomical localization of consciousness were battled around during the mid-1900s, and then during the 1970s the cortical theory began to be repeated long enough and loudly enough by prestigious enough experts that it eventually came to be taken for granted by everyone else as an established fact. Upon critical examination, the “evidence” turned out to be of an

exclusively negative nature: patients with diffuse cortical destruction do not manifest clinical signs of awareness of self or environment. But there was no positive evidence that such patients were not inwardly conscious.... PVS patients often grimace to noxious stimuli and manifest primitive withdrawal responses. Advocates of cortical theory write off such behaviors as mere brain-stem or spinal reflexes, but that dismissive attitude is based more on a priori assumption than scientific conclusion.²⁰

While Shewmon's critique is not a wholesale refutation of the current state of medical science regarding the PVS, it does call into question the traditional declarations of complete unawareness in the PVS. Shewmon's honest account of the origins of the cortical theory of consciousness is revelatory. At the very least, it shows that a great deal remains unknown to medical science regarding the human brain in general and in particular, the potential for consciousness in patients with a serious brain injury. At present many assumptions about persistent unconsciousness are being made that do a great disservice to the medical profession and the individuals who suffer from this condition.

Good reasons for uncertainty exist, and those reasons should not be summarily dismissed out of hand.²¹ While instances of a patient's recovery of consciousness from persistent unconsciousness are not everyday occurrences, they do happen on a not infrequent basis.²² In addition, discoveries of previously unknown capacities in the science of the brain are announced, again, on a not infrequent basis. For example, in 2006 a twenty-four-year-old woman, diagnosed persistently unconscious, exhibited a level of awareness not recognizable by normal observation. Using a functional MRI (fMRI) machine to measure neural responses, the woman was asked to imagine playing tennis and then to imagine walking through her home. Neural activity was recorded by the fMRI machine, and in each instance the levels measured were indistinguishable from the healthy control group.²³ The clinicians conducting the test concluded that the woman was able to comprehend verbal commands and to respond to them. They stated, "Moreover, her decision to cooperate with the authors by imagining particular tasks when asked to do so represents a clear act of intention, which confirmed beyond any doubt that she was consciously aware of herself and her surroundings."²⁴ Earlier this year a similar study was conducted with even more surprising results. Fifty-four patients were involved in the study, and of this group five patients showed awareness and cognition to a significant degree. By imagining tasks that stimulated either the motor or the spatial centers of the brain, the test subjects and clinicians were able to establish a simple "yes," "no" answering system. Verbal questions could be "answered" through the simple expedient of the patient imagining playing tennis or navigating the streets of a familiar city or the rooms of a familiar home.²⁵

The issue here is one of certainty. In cases like the ones mentioned above, it is possible that either the diagnosis is incorrect or the defini-

tion of PVS as a state of complete unawareness of self and environment is incorrect. Is it not possible that persistently unconscious patients might retain some level of inner awareness? Although only 10 percent of the 2010 study patients provided measurable responses to the questions posed to them, does this indicate that the remaining patients were completely unaware; or could it possibly mean that, at present, medical science does not possess the scientific and technological capacity to connect with them?

Moral Reflections

Introduction

From the beginning, the Church has been involved in promoting the dignity and the proper care of persistently unconscious patients. Similar to the actions of the medical community itself, several years passed after the conclusion of the *Quinlan* case to the time that the Church began to come to grips with the level of care owed to other patients like her. Unlike the direction taken by the medical community, however, the unique circumstances of patients in a state of persistent unconsciousness have remained an intensely debated subject in the area of moral theology. Over the past three decades the Church's response has been developed and refined as greater knowledge about persistent unconsciousness has intersected with traditional Christian anthropology and the guidelines for morally obligatory and morally optional methods of care and treatment. The Church's teaching on this subject culminated in Pope John Paul II's March 2004 allocution to an international congress titled "Life-Sustaining Treatment and the Vegetative State: Scientific Advances and Ethical Dilemmas."²⁶ Three years later The Holy Father's allocution was confirmed by a short declaration of the Congregation for the Doctrine of the Faith titled *Responses to Certain Questions Concerning Artificial Nutrition and Hydration*.²⁷ Most recently, adjustments to part five ("Issues in Care for the Seriously Ill and Dying") of the *Ethical and Religious Directives for Catholic Health Care Services* were made by the United States Conference of Catholic Bishops that reflected the improved clarity of the Church's position on this issue.²⁸ Here I intend to address some specific aspects of the Church's teaching and to examine some of the responses that have arisen in light of it.

2004 Papal Allocution

Although the 2004 allocution has its detractors, it is one of the defining documents in the long debate over the care of patients in persistent unconsciousness. It was delivered at a time when the deadlock among Catholic theologians was believed by many (including myself) to be nearly unbreakable, and it provided badly needed leadership for the care of such individuals. There are several aspects of the 2004 allocution that deserve special consideration.

First, even though the document is relatively brief it contains an unequivocal reminder that the inherent dignity possessed by all human beings is not lost as a result of persistent unconsciousness. Common use of the term “vegetative” when describing the condition of persistent unconsciousness was singled out as a demeaning adjective that “even when confined to the clinical context”²⁹ should not be applied to human beings. “The loving gaze of God the Father continues to fall upon them, acknowledging them as his sons and daughters, especially in need of his help.”³⁰

Second, the allocution offers a less technical, but actually a more accurate description of persistent unconsciousness. The Holy Father wrote that, “The person in a vegetative state, in fact, shows no *evident* sign of self-awareness or of awareness of the environment, and *seems* unable to interact with others or to react to specific stimuli.”³¹ Based on the negative nature of the evidence of unawareness and the not uncommon instances of a return to consciousness, it appears to be more honest to acknowledge the limits of medical science with regard to persistent unconsciousness, than to stubbornly insist on the phrase, “complete unawareness” when that does not always appear to be the case.

Third, the allocution lists the rights that are owed to patients who are persistently unconscious. Such patients deserve basic health care, including sustenance, appropriate rehabilitative care, and the right to be monitored for clinical signs of recovery. In this regard, it is not enough just to keep such individuals alive by warehousing them in a long-term health-care facility. They should receive care designed to assist in their recovery of consciousness as well. Further, the persistently unconscious patient has the right to be monitored for signs of recovery. This is not as easy as it sounds. A common caution promoted by many of the neurologists and other medical professionals who attended the 2004 international congress was that not just any physician or nursing professional was sufficiently trained to determine when a patient was beginning to recover consciousness. They pointed to recent studies in which the rates of misdiagnosis were reported to reach as high as 43 percent.³² Even as late as February of this year, the study published in the *New England Journal of Medicine* mentioned earlier stated that “the rate of misdiagnosis is approximately 40 percent.”³³ It does not take much imagination to wonder if some of those diagnosed persistently unconscious were actually minimally conscious, or at least retained some level of inner awareness, when their sustenance was removed so they would die.

By far, the segment of the papal allocution that received the greatest attention was the Holy Father’s statement about the administration of food and water. He said,

I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*. Its use, furthermore, should be considered in principle, *ordinary* and

proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.³⁴

Thus contrary to the conclusion of many in the American medical community and the American legal system, the Holy Father declared the delivery of assisted food and fluids to be a natural means of caring for a patient and not a medical treatment. Although at first glance this declaration on the nature of assisted food and fluids might seem presumptuous, as noted earlier, there is no conclusive argument that definitively classifies assisted food and fluids in either category. Some theologians argue that “all artificial feeding does is maintain the biological processes of the person. It does not directly contribute to the person’s recovery or maintain them in a stable condition as part of an ongoing therapeutic process.”³⁵ And they are correct. The benefit of assisted food and fluid provision is that the person’s body receives the nutrients and fluids necessary for continued life. On the other hand, setting aside the side-effects of taste and texture, is not meeting bodily requirements the primary purpose of ingesting food and fluids no matter what the person’s physical condition? Again, whether a person is young or old, male or female, sick or healthy, food and fluids maintain the biological processes necessary for life. Unlike true medical treatments, assisted food and fluids do not address a disease or the symptoms of a disease. Assisted food and fluids do not substitute for a lost function of the body as do life-sustaining measures like renal dialysis or mechanical ventilation. There are significant differences between the provision of food and fluids and the provision of medical treatments, and the Holy Father is correct in insisting that this difference be recognized.

Crux of the Matter

Without question the most controversial aspect of the 2004 allocution was the Holy Father’s declaration that food and fluids, even if assisted by artificial means are, in principle, an ordinary and proportionate means of preserving life. Within the Catholic moral tradition, an ordinary means of preserving life is morally obligatory and includes all medicines, treatments, and operations which offer a reasonable hope of benefit and which can be obtained and used without excessive expense, pain, or other inconvenience. Extraordinary means, by contrast, are morally optional and consist of all medicines, treatments, and operations which cannot be obtained or used without excessive expense, pain, or other inconvenience, or which, if used, would not offer a reasonable hope of benefit.³⁶ Critics of the allocution were quick to allege that by this statement the Holy Father had violated the traditional Catholic position which recognized the individual patient as the ultimate arbiter of what constituted an ordinary and what constituted an extraordinary means of preserving life.³⁷ They argued that if the Holy Father declared assisted food and fluids to be an ordinary means of preserving life where

was there any room left for the patient's reasoned assessment of the benefits or burdens of such an intervention.

The question raised here is a reasonable one. On this point critics of the allocution stood firmly in line with directive 32 of the *Ethical and Religious Directives of Catholic Health Care Services* which states that:

While every person is obliged to use ordinary means to preserve his or her health, no person should be obliged to submit to a health-care procedure that the person has judged, with a free and informed conscience, not to provide a reasonable hope of benefit without imposing excessive risks and burdens on the patient or excessive expense to family or community.³⁸

The Holy Father's statement was in error, they alleged, because apparently by *fiat* the pope had objectified the "benefit" of assisted food and fluid provision without allowing for the judgment of the patient.³⁹

Rebutting this interpretation, others pointed to the words "in principle," to indicate that this statement did not definitively classify assisted food and fluids as an ordinary means of preserving life. The caveat "in principle," did allow patients to determine the ordinary or extraordinary nature of food and fluid provision, while at the same time it focused attention on the nature of the treatment and the ease and effectiveness with which it sustained the life of patients who were persistently unconscious.⁴⁰ They argued, therefore, that although assisted food and fluids are not always and in every circumstance an ordinary means of preserving life, "in principle" or "generally," it should fall into this category because it provides a reasonable hope of benefit and can often be used without excessive burden, expense, pain, or other inconvenience.

So how do we assess the merits of these two interpretations? It is an area of great concern that a person's right to judge the ordinary or extraordinary nature of a particular intervention be recognized and his decisions followed. On the other hand, great care needs to be taken in regard to this right because it is not absolute; there are parameters for health-care decision making across which no person can morally transgress. The Church has always taught that God is the master of life and that human beings receive life from God and exercise a stewardship over it.⁴¹ Along these lines it would appear that directive 32 cannot be properly read without guidance from directive 28 and directive 59. Directive 28 states that "The free and informed health-care decision of the person or the person's surrogate is to be followed so long as it does not contradict Catholic principles." Directive 59 is similar. It asserts that: "The free and informed judgment made by a competent adult patient concerning the use or withdrawal of life-sustaining procedures should always be respected and normally complied with, unless it is contrary to Catholic moral teaching." In other words, while a person has great latitude in this area, and his or her free decision-making authority carries a great deal of weight, not every action or omission that a person might want to choose is a moral one. Some of the greatest difficulties that many

Catholic theologians have with the 2004 allocution appear to rest upon this particular issue.

Sometimes the parameters set forth by God become less clear. One of the common questions often heard regarding the maintenance of the life of dementia patients, late-term Alzheimer's patients, or persistently unconscious patients by means of ANH has been: "Would you want to live like that?" or "Would you tell your loved ones to continue to keep you alive in this fashion?" Similarly, a familiar lament often expressed during the *Schiavo* case was, "If only Terri had recorded her treatment preferences...." Of course the overwhelming presumption here was that she would have decided not to receive the food and fluids sustaining her life. The idea of the sovereignty of individual preference in medical decision making has been picked up by numerous individuals including some Catholic theologians. For example, Fr. John J. Paris wrote the following:

Let me give you a test that I've done 100 times to audiences. And I guarantee you can do the same thing. Go and find the first 12 people you meet and say to them, "If you were to suffer a cerebral aneurysm, and we were able to diagnose with a PET scan immediately, would you want to be put on a feeding tube, knowing that you can be sustained in existence?" I have asked that question in medical audiences, legal audiences, and audiences of judges.... How many people do you think have said they wanted to be maintained that way? Zero. Not one person.⁴²

Setting aside the blatant emotionalism that underscores Fr. Paris's "test," there are three (at least three) major problems with it. First, in a manner similar to the late Richard McCormick, S.J.'s three-hundred-bed scenario, it is an appeal to people's worst fears; and it forces them to make a response from a biased point of view, namely, from a position of health and vitality imagining a condition of significant debility. It is also a facile argument. I could just as easily say, "Let me give you a test.... If you were to walk into this room would you want someone to hit you over the head with a hammer? Not one person would say that they wanted that to happen. Zero. Not one person." Big shock there! Contrary to the ubiquitous American proclivity for unlimited dominion over my life and my body, within the framework of Catholic health-care decision making, the fundamental question here is not necessarily what I might want. There are many things that I might want or not want, but the means to achieve those desires are not necessarily moral. Many things may happen to me in my life that I would not necessarily choose. There are numerous responses to the situations with which I am confronted, but not all of them can be morally carried out. Emotional appeals to imagine the worst are unhelpful in cases like this. A common admonition in the medical field is "do not give patients false hope." By contrast, as I once heard Wesley Smith remark at a conference on end-of-life issues, we should also avoid "giving patients false despair." There is something

very Christian and holy about caring for patients, even those who are persistently unconscious, using reasonable means for the time that they have left in this world.

A second, and even more serious, problem with Fr. Paris's "test" is its apparent overemphasis on personal autonomy. That we are stewards of the gift of our lives means that human authority over life is not an absolute authority without limits. All of my health-care desires do not constitute an absolute trump in which my personal wishes and directives become paramount. Lately there has been a tendency to honor any claim of the extraordinary nature of assisted food and fluids without due reflection on the objective benefits or burdens of such an intervention. My concern here is not with the claims that assisted nutrition and hydration might involve an excessive burden that can be morally refused; ANH can become excessively burdensome, or it can no longer achieve its purpose. Rather, it is the fact that such claims often appear to be accepted at face value with apparently little or no legitimate questions asked.

At the same time, there has been a significant under-emphasis of other critical factors that might unduly color a person's assessment of food and fluid provision in the case of unconsciousness or incompetence. Pertinent factors such as the fear of losing control, dependence, the fear of being a burden, depression, fears about expense, an unwillingness to accept care or assistance, and the motives of family members (to name a few) are often overlooked in the face of a claim of the extraordinary nature of ANH. While the fears and concerns of patients must be taken seriously and not lightly swept aside, there are remedies and types of assistance for many of these concerns that do not end in death. Additionally, also forgotten is the duty to accept some inconvenience or suffering to maintain the good of life. As eighteenth-century theologian H. Tournely argued, although extreme pain or suffering does not impose an obligation on a person, one does incur a duty to accept an ordinary treatment that only involves a moderate amount of pain.⁴³

Third, a decision-making model that concentrates so heavily on an individual's wants and desires as an absolute trump can easily ride roughshod over a more reasoned assessment of a proposed medical intervention using the ordinary-and-extraordinary-means guidelines. Questions, such as "Would you want to live in such and such a condition?" or "What would you want?" in terms of treatment preferences, have their place. They can raise important issues for consideration; and within proper parameters, they are in line with the Catholic moral tradition. On the other hand, using them as the ultimate arbiter for the acceptance or refusal of treatment decisions effectively circumvents the ordinary-and-extraordinary-means guidelines, and opens up the possibility for quality-of-life judgments. Stated another way, questions that focus on an individual's wants and desires alone do not properly respect man's dependent status as a creature; nor do they adequately address

his moral obligation to preserve the good of his life using reasonable means. The Catholic moral tradition holds that as stewards of the life given to us by God we are bound to use reasonable means to sustain the good of our lives. The focus here is on any treatment that offers a reasonable hope of benefit and is not excessively burdensome, painful, or expensive, etc. To be clear, The Church's teaching is not a dismissal or a diminishment of an individual's right to honestly assess the benefits or burdens of a medical treatment or form of care and to subsequently make treatment decisions based on that assessment. On the other hand, it does not seem out of line to point out the potential for abuse that can occur by overstepping the bounds of limited autonomy and arrogating an absolute dominion over one's life.

In closing, human life, even in a persistently unconscious condition, remains a gift from God; and it is not completely our own to dispose of as we please. This is a fact of faith often at odds with the predominant thinking of American culture and consequently the prevailing wisdom in the practice of medicine and law. Nearly every health-care directive that I have ever seen simply asks people to check the boxes beside the types of treatment or care that they do not want in the event of incompetence, without any serious consideration of the larger human and moral issues. By contrast, the Church tries to uphold the dignity of the human person and to model the type of health care that all human beings deserve simply because they are human. The ordinary-and-extraordinary-means-of-preserving-life principles offer helpful guidance in determining what treatments, procedures, and operations offer a reasonable hope of benefit without being excessively burdensome. We have an obligation to rationally consider if a particular intervention is going to offer such benefit and to resist the lure of focusing solely on the value of the person's life. The clarifications from the Vatican, and now the U.S. Conference of Catholic Bishops on end-of-life care, charge us to honor human life, particularly when it is most vulnerable and to resist practices that, even if motivated by a form of compassion, nevertheless intend to end the life of a person whose life is judged to be devoid of sufficient quality.

Notes

¹ *Cruzan v. Director, Missouri Department of Health*, U.S. Supreme Court, 497 U.S. 261 (1990).

² Multi-Society Task Force on PVS, "Medical Aspects of the Persistent Vegetative State" (part 1), *New England Journal of Medicine* 330 (1994): 1499–1508; (part 2), *New England Journal of Medicine*, 330 (1994): 1572–1579.

³ Multi-Society Task Force on PVS, "Medical Aspects of the Persistent Vegetative State" (part 1), 1500.

⁴ D.E. Levy et al., "Prognosis in Nontraumatic Coma," *Annals of Internal Medicine* 94 (1981): 293–301. See also Multi-Society Task Force on PVS, "Medical Aspects of the Persistent Vegetative State," (part 1), 1503.

⁵ *In Re: The Guardianship of Theresa Marie Schiavo, Incapacitated*, no. 90-2908-GD-003 (October 11–22, 2002).

⁶ David Gibbs with Bob DeMoss, *Fighting for Dear Life: The Untold Story of Terri Schiavo and What It Means for All of Us* (Bloomington, MN: Bethany House Publishers, 2006).

⁷ The Multi-Society Task Force, “Medical Aspects of the Persistent Vegetative State” (part 1), 1503.

⁸ Christian J. Borthwick, LL.B., “The Permanent Vegetative State: Ethical Crux, Medical Fiction,” *Issues in Law and Medicine* 21 (1996): 170. See also the report of the Quality Standards Subcommittee of the American Academy of Neurology, “Practice Parameters: Assessment and Management of Patients in the Persistent Vegetative State (Summary Statement),” *Neurology* 45 (1995): 1017.

⁹ Richard A. McCormick, *Corrective Vision: Explorations in Moral Theology* (Kansas City, MO: Sheed & Ward, 1994), 232.

¹⁰ The Multi-Society Task Force, “Medical Aspects of the Persistent Vegetative State” (part 2), 1575.

¹¹ *Ibid.*, 1576.

¹² Bonnie Steinbock, “Recovery from Persistent Vegetative State? The Case of Carrie Coons,” *Hastings Center Report* 19.4 (July/August 1989): 14; “In the Matter of Carrie A. Coons,” *Issues in Law and Medicine* 9 (1993): 177. Wesley J. Smith, “Dehydration Nation,” *Human Life Review* 29.4 (Fall 2003): 69–79; Eugene F. Diamond, M.D., *A Catholic Guide to Medical Ethics: Catholic Principles in Clinical Practice* (Palos Park, IL: The Linacre Institute of the Catholic Medical Association, 2001), 103, 129; Ben Davey and Associated Press, “Man Wakes From Coma After 19 Years,” *Sydney Morning Herald*, July 9, 2003, <http://www.smh.com.au/articles/2003/07/09/1057430247106.html>.

¹³ 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* 39 (1989): 125–126.

¹⁴ Kirk Payne et al., “Physicians’ Attitudes about the Care of Patients in the Persistent Vegetative State: A National Survey,” *Annals of Internal Medicine* 125 (1996): 104–110.

¹⁵ Ronald E. Cranford, M.D., “A Hostage to Technology,” *Hastings Center Report* 20.5 (September/October 1990): 10.

¹⁶ Marcia Angell, M.D., “After Quinlan: The Dilemma of the Persistent Vegetative State,” *New England Journal of Medicine* 330 (1994): 1524.

¹⁷ President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forgo Life-Sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in Treatment Decisions* (Washington, D.C., U.S. Government Printing Office, 1983), 186; David Hilfiker, M.D., “Allowing the Debilitated to Die: Facing Our Ethical Choices,” *New England Journal of Medicine* 308 (1983): 717–718.

¹⁸ Council on Ethical and Judicial Affairs of the American Medical Association, *Current Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association* (Chicago: American Medical Association, 1986).

¹⁹ James L. Bernat, M.D., *Ethical Issues in Neurology* (Newton, MA: Butterworth-Heinemann, 1994), 148.

²⁰ D. Alan Shewmon, M.D., "Recovery from 'Brain Death': A Neurologist's Apologia," *Linacre Quarterly* 64.1 (February 1997): 59–60.

²¹ See Eugene F. Diamond, M.D., "Definitions of Therapy, Treatment and Care," in *Life-Sustaining Treatment and Vegetative State: Scientific Advances and Ethical Dilemmas* (Rome, Italy: Istituto per l'Analisi dello Stato Sociale, 2004), 23–24.

²² Jamie Talan, "To What Extent Do People with Consciousness Disorders Recover? Insights Offered in Two New Papers," *Neurology Today* 10.14 (July 15, 2010): 20; Bonnie Steinbock, "Recovery from Persistent Vegetative State?: The Case of Carrie Coons," *Hastings Center Report* 19.4 (July/August 1989): 14; Diamond, *A Catholic Guide to Medical Ethics*, 103, 129; Davey and Associated Press, "Man Wakes Up From Coma After 19 Years."

²³ Adrian M. Owen et al., "Detecting Awareness in the Vegetative State," *Science* 313 (2006): 1402.

²⁴ *Ibid.*

²⁵ Martin M. Monti, Ph.D. et al., "Willful Modulation of Brain Activity in Disorders of Consciousness," *New England Journal of Medicine* 362 (2010): 579–589.

²⁶ Pope John Paul II, "To the Participants in the International Congress on 'Life-Sustaining Treatments and the Vegetative State: Scientific Advances and Ethical Dilemmas,'" *L'Osservatore Romano*, English edition, March 13, 2004.

²⁷ Congregation for the Doctrine of the Faith, "Responses to Certain Questions Concerning Artificial Nutrition and Hydration" (2007), http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20070801_risposte-usa_en.html.

²⁸ United States Conference of Catholic Bishops, *Ethical and Religious Directives of Catholic Health Care Services*, 5th ed. (Washington, D.C.: USCCB, 2009).

²⁹ Pope John Paul II, "Life-Sustaining Treatments and the Vegetative State," 3.

³⁰ *Ibid.*

³¹ *Ibid.*, 2, emphasis added.

³² The issue of proper monitoring for clinical signs of eventual recovery continues to be a serious concern for some medical professionals. Citing the misleading behaviors of patients in the PVS, the lack of experienced medical personnel, and the limitations of existing assessment tools, Dr. Helen Gill outlined the difficulties inherent in properly monitoring patients in the PVS. As a participant at the 2004 international congress in Rome, Dr. Gill commented that the potential for misdiagnosis of the PVS continues to be a considerable likelihood. During the course of her presentation she stated the following: "There have been several studies which have shown that misdiagnosis of the vegetative state is very common. For instance, Tresh et al. found that 18% of long term patients in nursing homes in the U.S.A., diagnosed, as being in the vegetative state were able to communicate. Nancy Childs et al., found that 37% of patients admitted to her rehabilitative unit with a diagnosis of the vegetative state were aware. Research at the Royal Hospital for Neuro-Disability by Andrews et al. found that 43% of patients admitted with a diagnosis of VS for longer than 6 months were misdiagnosed, including several patients who had been thought to be vegeta-

tive for years.” Helen Gill, M.D., “Misdiagnosis of the Vegetative State,” in *Life-Sustaining Treatments and the Vegetative State*, 94.

³³ Monti et al., “Willful Modulation of Brain Activity in Disorders of Consciousness,” 579.

³⁴ Pope John Paul II, “Life-Sustaining Treatments and the Vegetative State,” n. 4.

³⁵ Thomas A. Shannon and James J. Walter, “Artificial Nutrition, Hydration: Assessing Papal Statement,” *National Catholic Reporter*, April 16, 2004, 10.

³⁶ Gerald Kelly, S.J., “The Duty to Preserve Life,” *Theological Studies* 12 (1951): 550.

³⁷ Thomas A. Shannon and James J. Walter, “Assisted Nutrition and Hydration and the Catholic Tradition,” *Theological Studies* 66 (2005): 661–662.

³⁸ United States Conference of Catholic Bishops, *Ethical and Religious Directives*.

³⁹ Shannon and Walter, “Assisted Nutrition and Hydration and the Catholic Tradition,” 665 and 661. They claim that the 2004 allocution contains a methodological shift away from the individual patient’s right to assess a particular form of medical care to a deontological approach that gives moral principles the greatest weight in health-care decision making.

⁴⁰ J.P. Hubert Jr., M.D., “Fr. Richard McBrien and Others Mislead Catholic Public: Allege Schiavo Feeding Tube Removal OK,” *Catholic Online*, March 8, 2006, <http://www.catholic.org/featured/headline.php?ID=3066>, 10. Dr Hubert asserted that, “As anyone even remotely familiar with gastrostomy tube feeding can attest, such feedings can be carried out in the home very easily by a family care-giver who employs a blender and regular food prepared for easy insertion into the tube.... Daily maintenance of the feeding tube requires minimal training and care. The initial placement of the feeding tube can be done without general anesthesia percutaneously in a few minutes at very low risk and without discomfort. From a medical perspective, it is a complete fabrication to claim that ‘tube-feeding’ represents extraordinary or disproportionate treatment/care.” Also Rev. Norman Ford stated that “The pope’s teaching applies in principle, but doctors and health-care providers still need to make clinical assessments to correctly determine when patients are being truly nourished and their sufferings alleviated, or when complications or other medical counter-indications arise.” Rev. Norman M. Ford, “Thoughts on the Papal Address and MANH,” *Ethics & Medics* 30.2 (February 2005): 4.

⁴¹ Pope John Paul II, encyclical letter *Evangelium vitae* (1995), n. 46 (AAS 87 [1995]: 34 § 4; English trans., [Libreria Editrice Vaticana, 1995], 39 § 1).

⁴² Andrew Leonard, “This Has Nothing to Do With the Sanctity of Life,” *salon.com*, March 22, 2005, http://dir.salon.com/story/news/feature/2005/03/22/father_john/index.html.

⁴³ H. Tournely, *Theologia Moralis* (Venetiis, 1756), tom. III, tract. “De Decalogo,” cap. 2 “De Quinto Praec.,” a. 1, conc. 2, in Daniel Cronin, *supra* note 67 at 67. C. Roncaglia divided surgical procedures into categories separating those involving intense pain from those only involving moderate pain. He considered only intense pain to involve a moral impossibility to accept, and thus he admitted the necessity to undergo moderate pain to conserve a person’s life. C. Roncaglia, *Theologia Moralis* (Lucae, 1730), vol. I, tract. XI, cap. I, q. III.