

THE DIGNITY OF BEING HUMAN

Examining Points Made by Cardinal Rigali and Bishop Lori Regarding Patients in the 'Vegetative' State

Catholic bishops and theologians have debated the proper care for patients in a persistent vegetative state for many years. These patients are perhaps more properly referred to as patients with persistent cognitive-affective deprivation,¹ or patients with post-coma unresponsiveness or unconsciousness.² These patients no longer have self-awareness, nor are they able to communicate or reason.³ They may continue to live for a very long time in this state.⁴ Theresa (Terri) Schiavo, for example, lived in a persistent vegetative state for 15 years and Elaine Esposito for more than 37 years. Recovery of any ability to think or exercise free will is extremely rare.⁵

In his March 2004 allocution, "Care for Patients in a 'Persistent Vegetative State,'"⁶ Pope John Paul II stressed⁷ the intrinsic value and personal dignity of every human being "no matter what the concrete circumstances of his or her life," and "... 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."

In August 2007, the Vatican's Congregation for the Doctrine of the Faith published "Responses to Certain Questions of the United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration." These responses were accompanied by a "Commentary" by the congregation.⁸ These documents confirm and explain John Paul II's 2004 allocution.

In *Health Progress*⁹ and *America*¹⁰, Cardinal Justin F. Rigali and Bishop William E. Lori express their concerns about a proper interpretation of the responses. Rigali is chairman of the Committee on Pro-Life Activities of the United States Conference of Catholic Bishops and Lori is chairman of the conference's Committee on Doctrine. They name the responses a "doctrinal reminder," an "authoritative statement of moral truth," and a reaffirmation of "a teaching by the Catholic Church's ordinary magisterium." The responses are not "merely a public policy statement." Although these articles by Rigali and Lori do not constitute an official statement by the conference, their authorship gives them a certain authoritative nature.

According to the authors, the articles were written to prevent "misunderstanding" and to correct "misrepresentation" of the authentic teaching of the church regarding artificial administration of food and water, to "help those involved in Catholic health care ministry more fully to understand the church's teaching," and to offer a critical review of certain publications.¹¹

A careful reading of the responses from the Congregation for the Doctrine of the Faith, along



BY FR. GERALD D. COLEMAN, SS, Ph.D., MARGARET MCLEAN, Ph.D., AND SR. JOAN MARIE STEADMAN, CSC

From left, Fr. Coleman is vice president, corporate ethics, Daughters of Charity Health System, Los Altos Hills, Calif., and lecturer, moral theology, Santa Clara University, Santa Clara, Calif. Dr. McLean is associate director and director of biotechnology and health care, and Sr. Steadman is associate director of health care ethics, both at the Markkula Center for Applied Ethics, Santa Clara University.

with their questions, gives a clear understanding of the authoritative teachings they contain:

- The administration of food and water even by artificial means is, in principle, an ordinary and proportionate means of preserving life.

- It is obligatory to the extent, and for as long as, it is shown to accomplish its proper finality, which is the hydration and nourishment of the patient.¹²

- Patients in a persistent vegetative state are persons with fundamental dignity.

- Artificial means of nutrition and hydration cannot be withdrawn even when competent physicians judge with moral certainty that this patient will never recover consciousness.¹³

Four points made by Rigali and Lori call for special attention in this article.

'IN PRINCIPLE'

Rigali and Lori state that the responses do not apply "solely to patients in a 'vegetative state,'" but also to patients who sustain "less extreme" conditions such as "chronic but stable debilitating conditions ... such as quadriplegia, mental illness or Alzheimer's disease."¹⁴ In reaching this judgment, they interpret the responses through the lenses of U.S. Catholic bishops' *Ethical and Religious Directives for Health Care Services*¹⁵ and the bishops' related "talking points."¹⁶

Directive 58 speaks of "a presumption in favor of providing nutrition and hydration to all patients, [emphasis added] including patients who require medically assisted nutrition and hydration," and the talking points maintain that the responses apply not only to patients in a persistent vegetative state, but also "to other patients."¹⁷ (No. 9)

The phrase "in principle" in the responses from the Vatican congregation plays a critical interpretative role. The responses do not aim at circumventing the reasoned decision of a patient or physician about whether or not the artificial feeding of a patient is of benefit. If a patient were dying, for example, tube feeding would be contraindicated. While the responses and the *Ethical and Religious Directives* present clear moral norms, specific clinical judgments must take place in the context of a patient's actual condition. As Smith and Kaczor note, "The pope is not claiming that food and water must be given in all circumstances whatsoever."¹⁸ Of primary consideration for Rigali and Lori is that they fear physicians

will withhold artificial nutrition and hydration from a patient simply because of a diagnosis of persistent vegetative state.

COST OF CARE

Although some maintain that artificial nutrition and hydration (hereafter ANH) does not involve excessive expense, Rigali and Lori make the important distinction that while "providing food and fluids generally accounts for a very small fraction of this [ANH] cost," the "complete range of long-term care for these helpless patients may indeed become very costly."¹⁹ In his allocution, John Paul II also acknowledged that families supporting relatives in a persistent vegetative state need support and "cannot be left alone with their heavy human, psychological and financial burden."²⁰ Rigali and Lori fear the overall financial burden might lead to putting "the caretaker's interests ahead of the patient's ..."²¹ Omitting

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necessary life-sustaining treatment cannot be justified by considering only the well-being of the caregiver.

It is critical not to downplay or minimize the question of cost. "Food and fluids" refer only to the nutrients and liquids supplied to a patient, and alone these are relatively inexpensive. However, the question becomes complicated when other factors are necessarily included, for example, the means used to administer the nutrients and fluids. Depending on whether they are administered via intravenous catheter, a nasogastric tube, or a percutaneous endoscopic tube, the costs of administration, replacement and clinical monitoring vary widely. Even the terminology of "artificial nutrition and hydration" is confusing. The calories and fluids received by a patient are not artificial. Rather, the means used to administer "food and fluids" are a medical artifact to assist patients who cannot eat or drink on their own.

In the actual context of health care today in the United States, the vast majority of patients who receive ANH do so in hospitals or long-term care facilities. Estimates for the procedures that enable

ANH vary from \$1,700 to \$2,000 monthly, while these estimates may go as high as \$5,000 to \$10,000 a month when the patient is in a hospital or nursing home. There are presently about 40,000 patients in this situation in this country. The general cost for caring for a single patient in a persistent vegetative state in the United States is \$126,000 to \$180,000 a year.

The Congregation for the Doctrine of the Faith's 1980 *Declaration on Euthanasia* teaches that a correct judgment of proportionate and disproportionate means is made by "studying the type of treatment to be used, its degree of complexity or risk, its costs and the possibilities of using it, and comparing these elements with the results that

One critical aspect of the authoritative nature of the responses includes the recognition of the "fundamental human dignity" of patients in a persistent vegetative state. Rigali and Lori emphasize that no patient's life is ever useless or burdensome. No matter what the clinical condition of a patient, his or her intrinsic human dignity is never forfeited.

can be expected, taking into account the state of the sick person and his or her physical and moral resources."²² *The Ethical and Religious Directives* also acknowledge that "excessive expense to family and community" is a serious consideration when informing one's conscience regarding "ordinary means to preserve his or her health." (Nos. 32, 56 and 57) Rigali and Lori wisely counsel that ANH cannot be "targeted for removal" for the sole purpose of "saving ... significant costs." In such a case, the patient is abandoned, and his or her "death is being intended precisely as a means to saving these other costs." Mindful of this important caution, the Catholic tradition includes cost as one of many criteria to be weighed when assessing burdens and benefits for patients and their families.

ORDINARY AND EXTRAORDINARY CARE

The Ethical and Religious Directives affirm the right of persons to "make an advance directive for their medical treatment" (No. 24) but also teach, as Rigali and Lori point out, that an individual patient's advance directives cannot be followed

by Catholic health care institutions if they are contrary to Catholic teaching.²³ Two considerations are in order:

First, the Vatican congregation's responses teach that "ordinary and proportionate care ... includes, in principle, the administration of water and food even by artificial means." Rigali and Lori interpret the phrase "in principle" to mean "as a general rule:"²⁴ that is, there is a "presumptive obligation to provide food and fluids as a form of ordinary care ..." The responses and commentary are clear when this general rule does not apply: ANH is not effective in hydrating and nourishing the patient, "emerging complications" demonstrate that ANH has become useless, ANH is "excessively burdensome for the patient," ANH is causing "significant physical discomfort, for example, resulting from complications in the use of the means employed," or ANH is "physically impossible."²⁵

The Catholic tradition on ordinary and extraordinary care provides helpful guidelines. Classical moralists such as Francisco de Vitoria and Dominic Soto, and the papal magisterium in the person of Pope Pius XII taught that "moral impossibility" might lead a person to make a decision that a certain type of care is extraordinary, disproportionate and therefore non-obligatory. Traditional examples included expensive foods and medicines, tremendous pain, and severe dread. In the 17th century, Cardinal Juan de Lugo used amputation as an example of extreme pain and asserted that a person is not obligated to undergo this surgery "if it is accompanied by very bitter pain ..."²⁶ A century before, di Vittoria wrote that "If the depression of spirits is so low and there is present such consternation in the appetitive power that only with the greatest of effort and as though by means of a certain torture, can the sick man take food, this is to be reckoned as an impossibility and therefore, he is excused, at least from mortal sin."²⁷

These respected moralists had a keen understanding and appreciation of spiritual and psychological suffering and the impact of subjective dread. Grave burden involves more than physical pain. It is possible that a means could be effective in prolonging life and, at the same time, involve a grave burden to the patient.

It is not a misinterpretation of this tradition to conclude that a person might find tube feeding "excessively burdensome." Rigali and Lori note that the "category of 'psychic burden'" suggested by John J. Hardt, Ph.D., and Fr. Kevin D.

O'Rourke, OP, JCD, STM, does "not justify ... the deliberate withdrawal of basic care owed to patients because of their human dignity." Psychic burden in the Hardt/O'Rourke article refers to the "aversion" others might feel toward "continuing care for comatose patients who will never recover consciousness." This is not the meaning of "moral impossibility," which refers to a patient's dread and fear of long-term tube feeding. Rigali and Lori emphasize that the category of "burden" does not mean "a simple dislike for survival in a helpless state."²⁸ This is correct, as Catholic theologians have traditionally viewed treatment as excessively burdensome if it is too "psychologically repugnant" to the patient.²⁹ It is not simply a matter of distaste.

Second, medical decision-making often relies on determining the benefits of a proposed intervention, its associated risks, and a calculation of whether or not the benefits are sufficient to outweigh the risks or the burdens. In general, physicians need not provide, nor patients undergo, interventions that are deemed disproportionate, that is, where the burden outweighs the benefit. Burdens may include insufficient efficacy, physical risk and discomfort, psychological burden, and economic imposition on the family. The *Declaration on Euthanasia* (1980) wisely indicates that when treatment decisions are made, "account will have to be taken of the reasonable wishes of the patient and the patient's family, as also of the advice of the doctors who are especially competent in the matter."³⁰

When assessing the actual situation of a patient, including a patient in a persistent vegetative state, the judgment might be made that ANH is ineffective. If such a patient is actively dying due to comorbid conditions, ANH is contraindicated. In the final stages of neurodegenerative disease, ANH can be profoundly burdensome to a patient. Medicine is a science of the particular and best practiced in context, that is, paying attention to this particular patient, with this particular diagnosis and prognosis, with these particular life goals, embedded in these particular relationships. This is why the responses employ the term "in principle" when speaking about ANH for the patient in a persistent vegetative state.

Consequently, a patient's advance directive might indicate that person's psychological dread of tube feeding, along with an expressed recognition that decisions in this regard be prudently made only in the specific context a patient might

face. Tube feeding is most effective, for example, in patients whose improvement and recovery goals are being met but who have difficulty swallowing. Head trauma, stroke, neurological disease, and upper GI obstruction from cancer of the neck and esophagus are among the most common conditions for considering tube feeding. In some circumstances, tube feeding is considered to be medically indicated, for example, for after-surgery care. Nevertheless, a reasonable person might regard tube feeding excessively burdensome because it causes great dread.

ETHICAL AND RELIGIOUS DIRECTIVES WITH REGARD TO ANH

Rigali and Lori state that "we fully intend that the next edition of the *Ethical and Religious Directives* will be amended to reflect this doctrinal clarification."³¹ At their June 2008 meeting in Orlando, Fla., officials of the United States Conference of Catholic Bishops gave permission to its Committee on Doctrine to begin a process of revising the *Ethical and Religious Directives* with regard to ANH. This revision is likely intended as an update rather than a change in the directives. Since the Vatican congregation's commentary states the revisions do not represent some new teaching, the *Ethical and Religious Directives* update is probably aimed at providing clarification on how directive No. 58 is to be properly understood and implemented in light of Pope John Paul's 2004 allocution and the Vatican congregation's responses. This understanding of the proposed update seems justified in light of the "Questions and Answers" statement of Sept. 14, 2007, by Catholic Health Association. "Will the [Vatican] document require a change in the *Ethical and Religious Directives*, namely directives 56, 57 and especially 58?" The reply is "No. The USCCB [United States Conference of Catholic Bishops] has been assured that the *Ethical and Religious Directives* are fine as presently written. These directives continue to guide decisions for patients in PVS."³²

One critical aspect of the authoritative nature of the responses includes the recognition of the "fundamental human dignity" of patients in a persistent vegetative state. Rigali and Lori emphasize that no patient's life is ever useless or burdensome. No matter what the clinical condition of a patient, his or her intrinsic human dignity is never forfeited. Human dignity is the starting point of Pope John Paul II's allocution: "... our brothers and sisters who

find themselves in the clinical condition of a 'vegetative state' retain their human dignity in all its fullness."³³

The radical revelation of our Christian faith is that even the least of our brothers and sisters bears the face of God.³⁴ Pope John Paul II affirmed in his allocution that "the loving gaze of God the Father continues to fall upon them [those in a persistent vegetative state], acknowledging them as his sons and daughters, especially in need of help."³⁵ No human life is to be deemed worthier than another. As Leon R. Kass has rightly stated, "Under no circumstances should we look upon a fellow human being as if he or she has a 'life unworthy of life' and deserves to be made dead."³⁶ The inviolability of human life rests absolutely on the higher dignity of human beings made in the image and likeness of God.³⁷

Br. Daniel P. Sulmasy, OFM, MD, Ph.D., has persuasively argued that intrinsic dignity is the fundamental basis for honoring the sick as human beings. "No circumstances can eliminate that intrinsic dignity."³⁸ Br. Sulmasy points out that proper care for patients in a persistent vegetative state and related neurological conditions has become "a highly contentious bioethical topic in the Western world."³⁹ Br. Sulmasy and many others agree with Pope John Paul II that even the word "vegetative" raises serious concerns of reducing a person to a vegetable.⁴⁰ Persons who have entered into this state have not lost intrinsic dignity. They are not "objects" to be euthanized or denied life-prolonging therapies. They have not undergone an ontological change. Rather, they are severely ill patients with a human dignity worthy of respect.

This doctrinal truth in the responses is captured well by Sulmasy: "Such individuals have an intrinsic dignity that also demands equality of treatment. Accordingly, such individuals cannot be denied access to care that other ill human beings would be afforded merely on the basis of their medical condition ... The diagnosis of post-coma unresponsiveness or unconsciousness itself ... must never be the basis for unilaterally withholding or withdrawing care that would be rendered to others."⁴¹ ■



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NOTES

1. Janet Smith and Christopher Kaczor, *Life Issues, Medical Choices* (Cincinnati: Servant Books, 2007), 112-115.
2. These terms were suggested for use in 2003 by the Australian National Health and Medical Research Council. The document is available online at www.nhmrc.gov.au.
3. In 1994, a Multi-Society Task Force built on a 1990 study of the Council on Scientific Affairs and the Council on Ethical and Judicial Affairs of the American Medical Association. They produced a "Consensus Statement on the Medical Aspects of the Persistent Vegetative State" and proposed seven criteria that were necessary before a patient could be said to have entered a persistent vegetative state: no self-awareness or interactive ability; no consistent purposeful responses to stimuli; no evidence of language expression or comprehension; intermittent sleep-wake cycles; sufficient hypothalamic and brain-stem function to allow survival with medical and nursing care; incontinence; and certain nerve reflexes.
4. For this reason, some clinicians suggest that persistent vegetative state is better described as a "permanent" vegetative state. See C.G. Gastrone, "Persistent Vegetative State: Clinical and Ethical Issues," *Theoretical Medicine* 18 (1997): 221-236.
5. Persistent vegetative state is classified as a "rare disease" by the Office of Rare Diseases of the National Institutes of Health. It affects less than 200,000 people in the U.S. population.
6. John Paul II, "Care for Patients in a 'Permanent' Vegetative State," *Origins* 33 (April 8, 2004): 737, 739-740.
7. In his 1950 encyclical *Humani Generis*, Pope Pius XII taught that whenever the Pope goes out of his way to speak on a disputed point, it is no longer a matter for free debate among theologians. Jesuit moralists Gerald Kelly and John Ford upheld this understanding by teaching that when the pope intends to settle a controversial issue in an address or talk, then theologians can no longer disagree. See John C. Ford and Gerald Kelly, *Contemporary Moral Theology: Questions in Fundamental Moral Theology, Vol. 1* (Westminster: Newman, 1958): 19-41.
8. The responses were signed by Cardinal William Levada, prefect of the Congregation for the Doctrine of the Faith, and approved by Pope Benedict XVI.
9. Justin F. Rigali and William E. Lori, "On Basic Care for Patients in the 'Vegetative' State," *Health Progress* 89, no. 3 (May-June 2008): 70-72.
10. Justin F. Rigali and William E. Lori, "Human Dignity and the End of Life," *America* 199, no. 3 (2008): 13-15.
11. Rigali and Lori specifically cite the following three articles: John J. Hardt and Kevin O'Rourke, "Nutrition and Hydration: The CDF Response, in Perspective," *Health Progress* 88, no. 6 (November-December 2007): 44-47; John J. Hardt, "On Church Teaching and My Father's Choice," *America* 198, no. 2 (Jan. 21, 2008): 12-15; and Thomas A. Shannon, "At the End of Life," *America* 198, no. 5 (Feb. 18, 2008): 9-12.
12. The question that leads to this first response asks whether the administration of food and water is

- obligatory if it causes the patient "physical discomfort." In light of the affirmative reply, this example should be understood as an essential part of the response.
13. This point is placed as a question and is given a positive reply in the second response.
 14. Rigali and Lori, "On Basic Care for Patients in the 'Vegetative' State," 70.
 15. We reach this conclusion because the responses speak only of patients in a persistent vegetative state.
 16. United States Conference of Catholic Bishops, "Vatican Affirms Church Teaching on Nutrition and Hydration for Individuals in 'Vegetative State'", www.usccb.org/comm.
 17. United States Conference of Catholic Bishops.
 18. Smith and Kaczor, 113.
 19. Rigali and Lori, "On Basic Care for Patients in the 'Vegetative' State," 71. In the *America* article, "Human Dignity and the End of Life," the same authors write on p. 15, "Assisted feeding is often not difficult or costly to provide in itself, but the housing, nursing care and other basic needs ... can be significant."
 20. John Paul II.
 21. Rigali and Lori, "Human Dignity and the End of Life," 15.
 22. Congregation for the Doctrine of the Faith, "Declaration on Euthanasia," *Origins* 10 (1980): 156.
 23. Rigali and Lori, "On Basic Care for Patients in the 'Vegetative' State," 71.
 24. Rigali and Lori, "On Basic Care for Patients in the 'Vegetative' State," 70.
 25. In such a case, the responses maintain that "minimal treatments" of comfort care remain mandatory and efforts should be made to obtain "the means necessary for an adequate support of life."
 26. Aaron L. Mackler, *Introduction to Jewish and Catholic Bioethics* (Washington, D.C.: Georgetown University Press, 2003), 87-88.
 27. Mackler.
 28. Rigali and Lori, "Human Dignity and the End of Life," 14.
 29. William E. May, et al, "Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons," *Issues in Law and Medicine* 2 (1987): 208. Also see Smith and Kaczor, 151-152.
 30. *Declaration on Euthanasia*, Part IV. Also see "Questions about Medically Assisted Nutrition and Hydration," United States Conference of Catholic Bishops, no. 4, www.usccb.org.
 31. Rigali and Lori, "On Basic Care for Patients in the 'Vegetative' State," 72.
 32. Catholic Health Association, "Comment Regarding Congregation for the Doctrine of the Faith Clarification Concerning Nutrition and Hydration for Patients in a Persistent Vegetative State," available online at www.chausa.org/pub/mainnav/newsroom/newsreleases/2007/r070914a.htm.
 33. John Paul II.
 34. John F. Kavanaugh, "Cicero and Jesus in the United States," *America* 198, no. 16 (May 12, 2008): 12.
 35. John Paul II.
 36. Leon R. Kass, "Defending Human Dignity" in *Human Dignity and Bioethics: Essays Commissioned by the President's Council on Bioethics* (Washington, D.C.: The President's Council on Bioethics, March 2008), 300. Available online at www.bioethics.gov.
 37. International Theological Commission, "Communion and Stewardship: Human Persons Created in the Image of God," *Origins* 34, no. 15 (2004): 233-248.
 38. Daniel P. Sulmasy, "Dignity and Bioethics: History, Theory, and Selected Applications" in *Human Dignity and Bioethics: Essays Commissioned by the President's Council on Bioethics* (Washington, D.C.: The President's Council on Bioethics, March 2008), 488. Available online at www.bioethics.gov.
 39. Sulmasy, 496-498.
 40. In his 2004 allocution, "Care for Patients in a 'Persistent Vegetative State,'" No. 3, John Paul II writes, "A man, even if seriously ill or disabled in the exercise of his highest functions, is and always will be a man, and he will never become a 'vegetable' or an 'animal.'"
 41. Sulmasy, 497-498.