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ARTICLE

Undue Burden?

The Vatican & Artificial Nutrition & Hydration

Consortium of Jesuit Bioethics Programs

Most Americans know the case of Terri Schiavo, the Florida woman who suffered cardiac arrest and subsequently lived for years in a persistent vegetative state while moral, legal, and political wrangles over her care divided her family and roiled the nation.

The Schiavo case highlighted the medical practice of providing artificial nutrition and hydration (ANH) to patients who can no longer swallow food or eat sufficiently well to sustain health or life. In the process, it prompted concern among many Catholic bishops, both in the United States and the Vatican, that ANH might be withdrawn from patients with the intention either of euthanasia or of ending a life that some people deem unworthy of further medical care. In July 2007, seven directors of bioethics programs at Jesuit universities came together to form the Consortium of Jesuit Bioethics Programs, dedicated to informing and influencing medical-ethical debates within the Catholic Church and the larger society. As one of our first outreach tasks, our consortium decided to address the subject of ANH.

First, some background on recent and pending church teachings concerning artificial nutrition and hydration. In 2004, John Paul II delivered an allocution on the use of ANH for patients in a persistent vegetative state (PVS). We strongly affirm his stance that all of human life deserves respect, and that health-care workers should not unilaterally deny patients treatments based on their own judgments of quality of life. However, the pope's statement included some assertions that surprised many involved in health care. One was that ANH "always represents a natural means of preserving life, not a medical act," and thus should be considered "morally obligatory." The pope stated furthermore that "no evaluation of costs can outweigh the value of the fundamental good which we are trying to protect, that of human life," and added that "society must allot sufficient resources for the care of this sort of frailty."

Some theologians believe these statements represent a departure from long-standing Roman Catholic bioethical traditions. The current U.S. Conference of Catholic Bishops' Ethical and Religious Directives for Catholic Health Care Services (fourth edition, 2001)—which guide all Catholic-sponsored health care in the United States—state that "a person may forgo extraordinary or disproportionate means of preserving life," and define such means as "those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community." The bishops' directives would appear not to align with John Paul's 2004 allocution in two important ways. First is their insistence that the decision of whether a "means" or treatment is ordinary (and thus obligatory) or extraordinary (and not obligatory) is based on the patient's judgment of that treatment's benefits and burdens. In contrast, the papal allocution defines ANH as ordinary and obligatory—regardless of the patient's judgment. Second, the Ethical and Religious Directives state that such a judgment may take into consideration a treatment's financial burdens to the patient, the patient's family, or the community; the papal statement, on the other hand, seems to prohibit such considerations.

Subsequent statements by the Congregation for the Doctrine of the Faith (CDF) and the Vatican have seemed to uphold a stringent reading of the pope's statement. A Vatican commentary on the CDF's response listed just three conditions when ANH might not be morally obligatory: (1) when it would be impossible to provide; (2) when a patient

may be unable to assimilate food and liquids; and (3) when ANH may be excessively burdensome for the patient or may cause significant physical discomfort, for example resulting from complications in the use of the means employed.

Catholics both within and without the health-care system are left with uncertainty about how to apply John Paul II's allocution. While the pope's statement referred specifically to the provision of ANH to patients like Terri Schiavo, who are declared permanently unconscious, some health-care workers worry about more general applications, for example, to patients with advanced Alzheimer's disease. Perhaps of most concern to those who work with gravely ill persons is a recent article by Bishop William E. Lori and Cardinal Justin Rigali (America, October 13, 2008), arguing that not everything in the CDF's "Responses" applies solely to patients in a persistent vegetative state, and specifically that ANH should be offered to patients with chronic but stable debilitating conditions less extreme than PVS. In June 2008, at the annual meeting of the U.S. bishops, Bishop Lori and Cardinal Rigali convinced the bishops to begin a process of amending the Ethical and Religious Directives, potentially extending recent teachings to new patient populations. The bishops may vote on these changes as early as June 2009.

In light of these ongoing actions, we offer some important facts and recommendations that might inform deliberations about artificial nutrition and hydration.

Though John Paul II explicitly maintains that providing ANH is not a medical act, the reality is that within the fields of medicine and law, the practice generally is viewed as a medical treatment. The most common way of administering ANH, through an endoscopic gastrostomy or PEG tube, involves a surgical procedure that requires both an anesthesiologist and a gastroenterologist, who inserts an endoscope through the mouth and esophagus into the stomach, then surgically opens the stomach to pass the tube through to the exterior of the body. Every patient with a tube requires skilled nursing care provided by a professional or by trained family members, frequent laboratory tests, and careful physician supervision, as the tubes have medical complications, including the possibility of life-threatening infections or even death.

Health-care costs associated with tube feedings are significant. Excluding the initial cost of surgery and the costs of caring for complications, which can be very high, health-care literature from 2007-09 estimates the annual cost of caring for a PEG tube at home to range from \$9,000 to \$25,000. However, many families cannot afford to take time away from their jobs to provide the necessary home care. At approximately \$60,000 per year, the cost of putting a patient with a PEG tube in a skilled nursing facility is also out of reach for many families.

From a legal point of view, while many state statutes set a stringent standard for the refusal of ANH, a 2002 review of statutory and case law published in the *Journal of the American Geriatrics Society* concluded that case law supports a "consensus that ANH is a medical treatment that can be forgone like any other treatment." In theory, and consistent with well-established professional norms requiring informed consent for medical interventions, a hospital that forced ANH on a patient who legally refused it could be accused of battery.

Without a doubt, ANH can benefit many patients. In cases of acute illness or trauma, the practice can provide support while patients heal; and in chronic and some terminal illnesses, it can extend life. Some patients in PVS or patients who suffer a stroke may live years longer with ANH than without it. Nevertheless, some who receive ANH do not clearly benefit. For example, persons with advanced dementia who receive tube feeding have the same life expectancy as those fed by hand. Similarly, several studies involving patients dying of cancer indicate that their life expectancy is not prolonged by ANH. We urge physicians to practice evidence-based medicine and to start ANH only when data indicate a reasonable hope of benefit.

We believe that when ANH is used inappropriately, as might be the case with many advanced dementia patients, such patients are denied the care they deserve. Feeding by hand puts the dying person in contact with caregivers and provides the tenderness of human contact. Hand-fed patients are also no more likely to experience aspiration pneumonia caused by inhaling food. In our view, tube feeding implemented for convenience, or to assuage the sensibilities of family, or for cosmetic reasons, is inappropriate. Although hand feeding takes more time, we urge families and health-care workers to provide hand feeding as an alternative to ANH whenever nutritional needs can

be met equally well in this manner.

We believe that ANH should be started whenever the likely benefits to a patient outweigh its burdens. However, the fact is that if patients or physicians in Catholic hospitals fear that ANH cannot be discontinued once it is started, then some physicians will be less likely to offer the option, even when it might be appropriate to do so as a short-term trial. Thus, patients, families, physicians, and nurses must be reassured by Catholic facilities that health care will not be provided without informed consent.

It is important to note that before the relatively recent development of ANH technologies, all patients who lost the ability to swallow—usually due to profound brain damage—died. While ANH may delay death in some cases, in many others the dying process will continue unabated. So while the denial of treatment for patients based on health-care workers' quality-of-life judgments remains a legitimate concern, so too do overtreatment and the failure to accept that some conditions, such as advanced Alzheimer's disease, are terminal and will cause death. As ethicists working in health care, we understand that both situations cause moral distress for physicians, nurses, social workers, and other care providers. Emotional and mental anguish can result from the inability to perform what one believes to be the appropriate moral action. This in turn contributes to burnout and a decreased quality of patient care. We recommend that the voice of health-care workers be heard throughout the current discernment process in the church and in specific cases of clinical decision making.

We wish to warn against making hasty generalizations from recent Catholic teaching on the use of ANH with patients in a relatively stable persistent vegetative state. Other patients' conditions and circumstances may differ significantly, and most decisions regarding medical intervention versus a focus on comfort care are made in far more ambiguous contexts, in which the best plan of care is not always obvious. Families typically wish to err on the side of "giving the patient every chance," but they seldom wish to put the patient through pain and suffering if little hope of recovery exists. And so they work with the health-care team to determine a plan of care that has a reasonable chance of benefiting the patient. It is important that we not preempt the good-faith efforts of families to discern which treatments are in the best interest of the patient and which are simply not worth inflicting. The Catholic tradition has generally manifested a healthy respect for the judgment of patients and their families in these situations.

As a general rule, health-care workers, families, and the magisterium all want what is in the best interest of patients. Discerning precisely what that is requires a conscience formed both by general principles provided by our Catholic tradition and by the concrete facts of a patient's circumstances and experiences. We believe that the current edition of the Ethical and Religious Directives properly acknowledges the importance both of long-standing principles and of individual discernment—and we hope that as the U.S. bishops consider revising specific directives, they will preserve that balance.

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