

Response to the Consortium of Jesuit Bioethics Programs Statement “Undue Burden?”

The Catholic Medical Association

Introduction

In the February 13, 2009, issue of *Commonweal*, seven directors of bioethics programs at Jesuit universities (the Consortium of Jesuit Bioethics Programs) discussed their understanding of recent magisterial teaching regarding artificial nutrition and hydration (typically called ANH, which we refer to as medically assisted nutrition and hydration [MANH]).¹ Since the Consortium recommended “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,” as representatives of the Catholic Medical Association, we would like to respond briefly to their statement.

We can find some points of agreements with the Consortium, namely, “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”; that we should avoid “hasty generalizations”; and that, “[a]s a general rule, health-care workers, families, and the magisterium all want what is in the best interest of patients.” We hope that we also can agree that choice of language is important in expressing respect for human life. Thus, we suggest that, in referring to patients in states of unconsciousness, we avoid the use of the term “vegetative” (e.g., “persistent vegetative state” or PVS), a non-felicitous term, as our late pontiff noted. A common effort to promote the use of more appropriate language will better serve the dignity of persons in such conditions. Here we will speak of patients as persons in states of minimal consciousness (SMC), or states of permanent unconsciousness (SPU).

The Linacre Quarterly 76(3) (August 2009): 296–303.
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0024-3639/2009/7603-0007 \$.30/page.

Response to Jesuit Consortium

Apart from these points of agreement and common effort, we think the Consortium's statement provides insufficient guidance on some matters, and fails to resolve misunderstandings on others. Here we will focus on several significant shortcomings in the statement. First, the Consortium perpetuates, rather than resolves, popular misunderstandings of this recent magisterial teaching, echoing the notion that it "represent[s] a departure from long-standing Roman Catholic bioethical traditions." However, there is no settled Church teaching that MANH is extraordinary medical treatment, as the Consortium implies. The introduction to part 5 of the *Ethical and Religious Directives* (ERDs), both the 1994 and 2001 editions, clearly indicates that the "morality of withdrawing medically assisted nutrition and hydration from a person ... in ... PVS" is a question requiring further reflection.² And the commentary of the Congregation for the Doctrine of the Faith, which accompanied its formal reply to questions raised by Pope John Paul II's March 2004 allocution, clearly describes the ways in which the issue of MANH has been addressed in Church teaching over the last twenty-eight years.³ Nor is it helpful for the Consortium to suggest that there is a conflict between the ERDs and authoritative magisterial teaching ("The bishops' directives would appear not to align with John Paul's 2004 allocution"). The preamble to the ERDs itself notes that "the Directives will be reviewed periodically ... in the light of authoritative Church teaching."

Second, the Consortium adds to the "uncertainty about how to apply John Paul II's allocution." The Consortium quotes Pope John Paul II's teaching only partially ("ANH 'always represents a natural means of preserving life,'" quoting John Paul, allocution, n. 4) and later implies that feeding by hand has been excluded by papal teaching. In fact, in that passage, Pope John Paul II said, "the *administration of water and food*, even when provided by artificial means, always represents a natural means of preserving life, not a medical act" (emphasis added). Next, the Consortium fails to fairly consider the meaning of the pope's statement regarding the term "medical act," and then exhibits an undue deference to legal and medical authorities in resolving the issue.

We think the pope's meaning can be better appreciated by considering the example of childbirth (which is no more a medical act than MANH). Although childbirth has been "medicalized" in significant ways over time—medical specialists attend the expectant mother, anesthesia may be provided, surgery is sometimes needed, there are known risks and complications—still, in essence, the act of bearing a child is not a medical act. Similarly, the provision of food and hydration, either for oneself or someone else is not a medical act, even when it has been "medicalized." Conversely, we ap-

appropriately consider appendectomy for appendicitis, or coronary artery bypass surgery for heart disease medical acts. The essential difference between what is considered a medical act or not is the application of medical science and judgment for the treatment of disease, not simply the medicalization of something wholly natural and a part of usual human life.

The Consortium's deferential appeal to statutory, case law, and medical authorities in resolving this issue is misplaced and potentially dangerous. While appeals to legal and scientific authorities are necessary and helpful in policy matters, they are not sufficient to settle issues of morality, including our moral obligation to care for the sick, injured, and dying. And we need only recall the recent practice of defining abortion as "reproductive medicine" and attempts to define assisted suicide as "compassionate end-of-life care" to understand the danger of this line of thought.

Third, as physicians, we think the Consortium's recommendation to start MANH based only on evidence-based data is unsound. Much of medicine is not evidence-based in the strictest sense of the term. Moreover, evidence-based research is fraught with methodological challenges, some of which are presently insurmountable, and subject to underlying assumptions regarding "quality of life" and other similar notions which may in fact degrade the dignity of the patient and devalue his or her life. Until medical science can reliably offer sound evidence-based data, especially in weighty matters that concern the fundamental ethical principles of care, it is not advisable to rely so exclusively on such techniques of evaluating clinical care, particularly for vulnerable patients. For many patients, including patients in SMC and SPU, MANH contributes significantly to comfort, health, and survival. Where, due to decline of patient's status or accompanying complications, patients do not benefit from MANH, there is no obligation to provide it. We are convinced that good doctors, following both the highest standards of ethics and sound scientific medical practice, can treat patients appropriately.

Clarifying Principles

The Consortium statement raises a series of questions, yet does not evidence a sound methodology for resolving them. We believe health-care providers and patients can better apply the Church's teachings to the complex clinical, legal, and ethical issues inherent in providing nutrition and hydration to sick, injured, and dying patients by being cognizant of and respecting the core principles at stake. Here is a brief annotated summary.

1) Provide basic care and ordinary treatment. *There is a fundamental ethical obligation (and good) for individuals and society to provide basic care and ordinary treatment to the sick, injured, disabled, and dying.* The

basic principles have been outlined well in the *Declaration on Euthanasia*. The March 2004 allocution and subsequent Congregation for the Doctrine of the Faith response have clarified the place of MANH in the context of providing necessary care to the sick and dying.

2) Make sound and ethical recommendations. *Physicians and other health-care providers have an obligation to make treatment recommendations based on sound clinical and ethical criteria.* Within the context of always providing basic care and ordinary treatments, a physician must make a clinically and ethically sound decision about how to best meet a patient's need for nutrition and hydration. Professional- and legal-society opinions about MANH cannot replace sound clinical and ethical criteria.

3) Form one's conscience. *Persons (human persons, including patients, relatives, surrogates, and health-care professionals; and corporate persons, including institutions) have an obligation to base decisions and policies on a well-formed conscience and sound ethical principles.* People will continue to struggle with issues surrounding care of the dying. There need be no question of violating informed consent or disregarding the feelings of allied health workers. Rather, there is a need to help patients and surrogates to make informed decisions that will truly respect a patient's physical well-being and human dignity. And there is a need to take account of the perspectives of health-care providers involved in the care of patients even while evaluating those perspectives within a broader clinical and ethical framework, including the impact on family members who may bear considerable mental and emotional trauma from participating in the active euthanasia of a loved one. All Church teaching, including the March 2004 allocution and the Congregation for the Doctrine of the Faith's response, should be viewed as aids in helping to conduct these processes of informed consent and dialogue with integrity. If agreement between providers and patients about a plan of care cannot be reached, then the conflict must be resolved with ethical integrity.

4) Follow one's conscience/refuse unethical actions. *Physicians and health-care providers have an obligation to follow their well-formed conscience, to respect differing wishes when this is ethically permissible, and to refuse to cooperate in actions that are unethical.* If a patient or surrogate refuses care and that refusal will result in harm or death, a Catholic physician and/or health-care institution should not cooperate, but rather should recuse themselves and transfer the care of the patient to others.

5) Care for others. *Society has an obligation to care for those unable to take care of themselves.* It is not true to say that the March 2004 allocution ignores or prohibits recognition of the role of costs. Rather, it recognizes that cost must not be a determining factor in deciding whether to offer mini-

mal care and treatment to persons. If necessary, society should help families to bear the burden of caring for the sick, injured, disabled, and dying. We should be wary of rationalizations that send the message to dependent people (both healthy and unhealthy) that they are a burden that should be removed.

Recommendations

In conclusion, the CMA proposes the following points regarding the provision of MANH to vulnerable patients, particularly to patients in minimal or permanent states of unconsciousness.

Support for Church Teaching

- The Catholic Medical Association reaffirms its support for enduring Catholic teaching on the principled presumption of providing of nutrition and hydration to sick or injured patients unable to eat or drink on their own.
- The Catholic Medical Association recognizes that Pope John Paul II's March 2004 allocution and the August 2007 response from the Congregation for the Doctrine of Faith did not change or revise Catholic teaching on the matter of MANH, but rather clarified the content of the moral obligation to care for patients, in particular with the singular diagnosis of PVS.

Ethical, Clinical Care

- While aspects of providing MANH involve medical procedures, MANH itself in essence is not a medical act. As such, the provision of MANH is in principle, ordinary care.
- Hand feeding should never be withheld nor forgone if feasible. Even in cases of aspiration risk, it may be prudential to allow feeding in certain circumstances (e.g., very elderly patients).
- When hand feeding is not feasible, MANH in diagnoses other than persistent "vegetative" state can be best determined by the clinical judgment of a physician with a properly formed conscience, taking into account risks, benefits, burdens, available best medical evidence, and the patient's or surrogate's informed moral-medical choice.
- While there is no moral obligation to provide nutrition and hydration when these are ineffective (e.g., for patients who are dying), and while there are terminal diseases, such as advanced malignancy and end-stage cardiac/pulmonary disease, in which patients do not benefit from prolonged attempts at tube feeding, there are some cases where providing MANH

can help to ease the suffering of a terminally ill patient, e.g., by reducing symptoms of dehydration and malnutrition. Where there is reasonable doubt, responsible physicians should advocate for adequate levels of nutrition and hydration (including MANH), unless it is shown to be ineffective or counter-productive. Patients who develop terminal conditions should have MANH assessed periodically for risks, benefits, and burdens.

- Patients, surrogates, and physicians are not bound to the use of MANH in circumstances of physiological futility. If death is imminent, or the application of MANH is simply not feasible (e.g., inability to assimilate the material, lack of resources), then the threshold of immorality is not breached
- Some patients may find some delivery systems of MANH repugnant and wish to forgo it on a morally unacceptable basis. The physician should recognize this, and approach discussions with the patient and family or surrogate with sensitivity and prudence, explaining the benefits of nutrition and hydration for the patient and exploring all possible ethical options.
- MANH should never be refused, withheld, or withdrawn as a means to end life or suffering. When MANH is withheld or withdrawn, it must be on the basis of morally sound clinical grounds. If the refusal of MANH is thought to significantly alter survival, the clinician must confront the stark possibility that he or she is cooperating in an act of passive euthanasia.

***Care for Persons in States of Minimal (SMC)
or Permanent Unconsciousness (SPU)***

- Clinicians should be aware that the diagnosis of an SMC requires several weeks of being in a wakeful, but unconscious state, and that it takes a year to be considered in this state “permanently” (SPU). Spontaneous recovery from these states has been reported, and medical science is still unable to distinguish those who can recover from those who will not.
- The presence of an SMC or SPU in itself should not be considered a terminal disease.
- A Catholic physician cannot in good conscience order the discontinuation of MANH with the singular diagnosis of an SMC or SPU. To do so would be a violation of the physician’s duty to provide ordinary care. If the patient’s family insists on the discontinuation of MANH in this case, the physician must

recuse himself or herself from the patient's care. The same prohibition for removal of MANH also applies to Catholic health-care facilities. If care must be transferred because of irreconcilable views, such transitions of care should be done in an orderly, deliberate, and compassionate manner.

- The conscience of health-care workers must be protected in law and practice. Such conscience protection should be expanded to include Catholic institutions. The immoral withdrawal of hydration and nutrition cannot be carried out by a Catholic doctor or health-care system

As physicians, we realize the complexity of responding to the needs of each patient, particularly the profoundly sick or injured patients for whom MANH is a possible option. While there is a range of issues on which people of good will can legitimately disagree, we think that patients, families, and the health-care profession are well served by clear ethical guidelines. The CMA looks forward to working collaboratively with other health-care providers, patients, bishops, and priests to clarify and apply Catholic principles in health-care delivery for the ultimate benefit of our patients and society as a whole.

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