Redefining Death as a Way to Procure More Vital Organs: A Response

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Recent ethical literature on organ donation in the United States focuses on the reality that there are far more patients on a waiting list for a transplant than there are donors. It is estimated that there are approximately 170,000 people living today in the United States who are recipients of an organ donation, yet as many as 7,000 patients die annually because there are not enough organs available. It may be of interest to note that the 2007 Organ Procurement and Transplantation Network reports that in 2006 the increase in the number of living donors was lower than in any previous year. That year saw a 6% increase in deceased donors, but only a 2% increase from living donors. Not surprisingly, the ethical literature looks at the ethical issues related to increasing the availability of organs from deceased donors. This has resulted in a good deal of ethical discussion about the definition of death, who should be considered to be dead, why they should be thought to be dead, and whether or not it even matters if a person is dead in the procurement of vital organs. These questions are the focus of this analysis.

Defining the moment of death
The importance of an informative and practical definition of death is grounded in the traditional belief that before vital organs can be retrieved from a person, that person must first be known to be dead. This has come to be known as the ‘dead donor rule’: a person must be dead to be a donor of vital organs. The standard definition of death in use since before the 1960s spoke of the permanent and irreversible cessation of cardiac and pulmonary activity. The definition is descriptive of what death looks like so that it can be recognized. Once recognized, decisions about what can be done with the person’s body can be made, including vital organ retrieval. When someone had permanent loss of cardio/pulmonary function, it could be determined that the person was dead and their vital organs retrieved.

An early challenge to the cardio/pulmonary definition came with the development and widespread use of CPR in the 1960s. With CPR a heart could sometimes be restarted, raising the prospect that if a heart stopped but could be restarted, the person was not dead — at least not yet — because the cessation was not clinically irreversible. Concern about irreversible cessation of the heart was part of the discussion in 1967 when Dr. Christian Barnard performed the first heart transplant in South Africa. Much controversy resulted at that time over questions as to whether the donor was in fact dead when his heart was procured precisely because it was restarted in the recipient. By the standard descriptive definition the donor was not technically dead; the dead donor rule had been violated.

The ability to restart cardio/pulmonary function made necessary a hermeneutical nuance with the standard definition: irreversible cessation has come to be understood not as physiological irreversibility, which may not exist, but as ethical and legal irreversibility. That is, when there is no ethical or legal obligation to attempt to rescue someone with cardio/pulmonary resuscitation (CPR), the cessation is ‘ethically’ or ‘legally’ permanent, even if not physiologically permanent. It is, therefore, not necessary to attempt CPR in every instance in order to determine physiological permanence of cessation, and it is permissible to restart cardio and/or pulmonary function in a donation recipient. A person is dead when there is no legal or ethical obligation to respond to cardio/pulmonary cessation that is not followed by spontaneous resuscitation. Such persons are dead, and hence may be donors of vital organs according to the dead donor rule.

A second challenge to the standard descriptive definition of death came from those patients who suffered severe neurological damage and seemed to look alive only because they were attached to life-sustaining machines. The Harvard Medical School offered a resolution to this problem in 1968 by expanding the definition of death to include what
has come to be known as “brain death.” This definition of death was incorporated into the Uniform Determination of Death Act in 1981. In this new context, death can be defined as the irreversible cessation of all brain activity, including the cortex (higher brain) and the brain stem, irrespective of cardio/pulmonary function. As with the more traditional definition, the definition of brain death is also a descriptive or informational definition – it gives the information needed to know whether someone is alive and whether that person may be envisioned as an organ donor under the dead donor rule. With both the cardio/pulmonary and brain function definitions for death, death can be determined, and the dead donor rule preserved in the retrieval of vital organs from donors.

Challenges to a descriptive definition of death — being ‘dead for the purpose of’

As early as 1975, before the brain death definition was incorporated into the Uniform Determination of Death Act, and since, the narrowness of the brain death definition has been challenged. An early and continuing leading writer on the subject is Robert Veatch. In a 1975 article, Veatch called for a definition of death that allows simply for the irreversible loss of the ‘higher brain,’ the cortex, as a definition of death. This change would allow more people to be understood as being dead and, therefore, available as donors of vital organs under the dead donor rule.

Veatch has suggested that people who want to be organ donors upon their death should be able to choose between higher brain, whole brain, or cardiopulmonary definitions of death. Patients should be able to choose the definition that best fits their desire to be a donor as well as their own particular religious, cultural, or personal beliefs. What is important to note is that this discussion is not about a definition of death per se, a definition that allows us to know when someone is dead, but about creating a definition of death that will allow a greater number of organ donations. The definition is less about a description of the moment of death than it is about defining someone as being dead for the purpose of retrieving vital organs. In theory, someone could be understood to be dead according to one of Veatch’s three different criteria of personal choice. Each criterion could make someone ‘sufficiently dead,’ or to use the expression of Jay Baruch, ‘dead enough’ to be a deceased donor.

Because of the change of context from a definition of death per se to an understanding of who is ‘dead enough’ to be a donor, we also see a change in the nature of the definition itself. It is no longer descriptive and informational. The definition is now utilitarian, giving a definition of the patient’s usefulness or availability as an organ donor. The definition is not meant to say what death itself looks like, but to say if it is possible to consider someone as an organ donor. Under this scenario, it would be possible to have two patients with exactly the same neurological devastation in the same ICU, one who is ‘dead enough’ to be a vital organ donor because he or she wanted to be such, and the other who is not ‘sufficiently dead,’ because perhaps their religious tradition prohibits organ donation. The dead donor rule is preserved, but the definition of who is dead becomes highly situational and utilitarian.

Not being dead at all — giving up the dead donor rule

The debate about whether someone can be considered dead for the purpose of being an organ donor is only one part of the discussion. In 2003, Elysa R. Koppleman proposed that donation of vital organs need not be restricted to deceased donors, and hence any definition of death is not especially important. Such donations she argues should be allowed from living patients with irretrievably lost higher brain function; i.e., people who are permanently unconscious.

Koppleman’s ethical justification for this is that such a donation, and the patient’s subsequent death, would be done only when it was consistent with the donor’s particular history and interest.

Veatch, commenting on Koppleman’s 2003 article, notes that she is offering the same policies for organ procurement that he would like to see. The difference is that Veatch views the donor as dead and so the dead donor rule is preserved, whereas Koppleman abandons the dead donor rule and hence sees many of the same donors as alive. The chief point of disagreement is whether or not the patient should be understood as being dead. They do agree on a utilitarian policy that sees the clinical state of the patient (dead because of neurological devastation or alive with neurological devastation) as being defined for the purposes of organ donation.

Although they agree on who can be a donor, even if they
disagree on whether or not that donor is dead, they do not agree on the same strategy for increasing the number of organ donations, and this is insightful. Veatch claims that doing away with the dead donor rule, as Koppleman suggests, would require too many legal changes and weaken societal prohibitions on killing. He concludes it would be easier and less controversial to simply change the definition of death so more people fit the dead donor rule as a way of procuring more deceased donations.\textsuperscript{12} That, it seems to me, reveals a clearly utilitarian approach toward increasing the number of organ donations.

Robert Troug offers an interesting twist to this discussion in articles in 2003 and 2008.\textsuperscript{13} He writes that ultimately whether the patient is considered dead for the purposes of donation, as Veatch says, or alive but available for the purposes of donation, as Koppleman says, is not important. Instead, what is needed is simply a correct understanding of the ethical principles of nonmaleficence and autonomy in the allowance of all donations. Nonmaleficence holds, when applied to organ donation, that no one be harmed in the taking of their organs. From this principle, Troug concludes that we may take these vital organs from patients who are neurologically devastated or imminently dying. Such patients it seems, whether we think of them as dead or alive, cannot be harmed by the loss of their heart, lungs, kidneys, livers, pancreas, etc. Autonomy holds that we need patient consent, and that all we need is patient consent. As long as there is proper consent to the donation, everything that does not harm is permissible. Again, whether or not the patient is technically dead or alive is not determinative.

A response

James McCartney writing in 2004 offered a critique of Koppleman's abandonment of the dead donor rule, but his critique is applicable to the positions of Veatch and Troug as well.\textsuperscript{14} He doubts, purely as a practical matter, whether Koppleman's goal of procuring more organs by doing away with the 'dead donor rule' and taking organs from some living patients, can succeed if the general public senses that there is ambiguity about whether the donor needs to be dead first. One might make the same critique of Veatch's suggestion that one might be able to be 'dead enough' for purposes of vital organ donation if people could choose between higher brain, whole-brain, and cardiopulmonary definitions of death.

For my part, I hold ethical concerns about a shift from an informational and descriptive definition of death, a definition that tells us if one is dead, to a utilitarian definition, a definition that tells us if one is sufficiently dead or dead enough ‘for the purposes of’ organ donation. There is a critical need to increase the number of organs for donation, but such a utilitarian approach is to me hubris. Death is the ultimate existential moment of being, after which we materially cease to be. Death defies purposefulness — death perse is never for the purposes of something else. When we die we simply cease to be in this world. Whatever our religious or spiritual beliefs about what does or does not come after death, death itself is the end of our material being in this world. It is possible that some good may come out of one's death, such as saving lives by donating organs. Death perse, however, is not death for that purpose; people do not die in order that organs might help others live, even if their death is ordered in such a way as to provide for that donation as in organ donation after cardiac death.\textsuperscript{15} Death is the end of physical life — what we do with that end is another matter.

A predominantly utilitarian approach to defining death, or procuring organs from the living, raises for me a concern about the slippery slope: Where does such an approach to ‘being dead for the purposes of’ lead? If it can be that a patient is dead for the purposes of organ donation, might they also be able to be dead for other purposes, such as research? I can only imagine the medical strides we could make if we were able to declare people in a permanent vegetative state legally dead for the purposes of research. Once we decide someone can be dead for the purposes of one social good, I am not sure of the criteria to be used to decide if they are dead for the purposes of some other social good.

Finally, this approach, particularly as presented by Troug, over-plays I think the role of consent in ethical analysis. For many ethicists and clinicians, it seems consent is the determining factor in defining the moral status of an action. If the patient or appropriate surrogate has consented and the procurement is not harmful to the patient, death notwithstanding (Troug), then organ procurement is by definition permissible, whether it is a matter of considering this particular person dead (Veatch) or taking the organ when the person is by definition still living (Koppleman). In fact,
consent is not nearly so powerful ethically. Consent in the ethical tradition is a permission to do what is right; it does not make what is done right. Consent is not, like Double Effect, a principle of justification that allows in a particular situation what is otherwise ethically questionable or prohibited. Consent merely allows one to act on an otherwise good option; it does not make the option per se to be ethically good.

**Conclusion**

“Knowing when death has come, along with what can and should be done before and after it has arrived, has always been a problem for humankind, to one degree or another.”16 The 1981 report of the Presidential Commission determined that one is dead in circumstances of irreversibly lost cardiac and respiratory function and/or irreversible loss of total brain function.17 Moving from these descriptive definitions to a utilitarian definition seems to me to open the door to approaches to definitions of death that have more to do with the procurement of organs than with knowing when a loved one has died, and the time to grieve has arrived. With Hans Jonas in 1974, and to a large degree with the President’s Council on Bioethics in 2009, I challenge the undue precision of our definition of death, and its application to the social need for organs.18 With my colleague Art Caplan, I agree that “people are getting nervous when we're pushing the standard of death in order to get organs. The public is afraid that surgeons in search of organs for transplant will bend the definition of death to get them.”19

A descriptive, informational definition of death, irrespective of its usefulness for obtaining organs for donation and transplant, seems to me to be the most ethical approach to understanding and diagnosing the moment of death.

**NOTES**

6. Because brain activity, unlike cardio/pulmonary activity, cannot be resuscitated, irreversibility is both physiological and ethical/legal.
Promoting Human Dignity Through Tube Feeding: Finding the Mean*

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As those who are integrally involved in the delivery of end-of-life care know far better than I do, there comes a point when the task of medicine becomes primarily, if not solely, to care because it can no longer cure. Perhaps one of the most important virtues for those who provide care for those living with a life-threatening illness or injury is the ability to know when this moment has arrived — not an instant premature, but not so late that the dying person endures additional suffering.

This virtue is the capacity for a truly prudential moral judgment regarding the use of life-sustaining technology within the Catholic moral framework. The Ethical and Religious Directives for Catholic Health Care Services, 4th ed. (directives) articulate the basis for such judgments in the following manner:

"The use of life-sustaining technology is judged in light of the Christian meaning of life, suffering and death. Only in this way are two extremes avoided: on the one hand, an insistence on useless or burdensome technology even when a patient may legitimately forgo it and, on the other hand, the withdrawal of technology with the intention of causing death." (Part Five, Intro.).

While the explicit focus of this passage pertains to the use of life-sustaining technology, I would submit that the real concern is actually more about respecting the human dignity of those near the end of life than it is about the use of technology itself. In this sense, the directives are articulating that old Aristotelian (and Thomistic) theory of virtue as the mean between two extremes, applied specifically to the question of how best to respect human dignity at that point in a person's life when he or she is most vulnerable.

In the remainder of this essay I will attempt to illustrate the significance of avoiding such extremes, by considering the example of “tube feeding,” or medically assisted nutrition and hydration, through the lens of the directives, particularly No. 58.

**Considering Directive No. 58**

Contrary to popular opinion, or what I can only surmise is popular opinion based on my own experience as an ethicist working in Catholic health care, Directive No. 58 is not primarily about “tube feeding.” Rather, the directive is primarily about providing “nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration. …” The very fact that the subject of this directive is the provision of “nutrition and hydration” and that the object is “all patients” tells us that the predominant concern is not about “tube feeding” per se, but about the benefit that tube feeding provides by satisfying basic physiologic needs (when in fact it does so). Indeed, “medically assisted” nutrition and hydration is mentioned only as a qualifier. Yet, this directive recognizes that the value of satisfying such basic needs can be counterbalanced by burdens associated with medical assistance, where the directive says, “so long as this is of sufficient benefit to outweigh the burdens involved to the patient.”

Implicit in this directive are a number of presuppositions worth noting. First, the satisfaction of the physiologic need for nutrition and hydration is always a benefit. In other words, one cannot – consistent with the Catholic moral tradition – say that satisfying this need is never a benefit or of no benefit whatsoever. Yet, this directive also presupposes that there may be times when “tube feeding” is medically contraindicated, either because the body can no longer assimilate it or because excessive clinical burdens may be associated with the tube. Accordingly, it is not always and necessarily the case that the benefit is sufficient to warrant its provision. In this way, Directive No. 58 leads us away from the two extremes of “never” and “always” and guides

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us toward that virtuous mean through which human dignity can best be served.

Also, implicit in this directive is the presupposition that there may be means other than tube feeding for providing nutrition and hydration. In many circumstances, hand feeding may be a scientifically sound option for patients who are unable to feed themselves but are still able to take at least some nutrition and hydration orally. One of the downsides of tube feeding is that it reduces the interpersonal and social dimensions of the interaction between staff doing the feeding and vulnerable patients receiving the nutrition and hydration. A significant advantage of hand feeding with respect to promoting human dignity is that it can accomplish the same physiologic goal, while fostering a more intimate and caring relationship — a human connection — between the person doing the hand feeding and the patient. While tube feeding is often the most efficient way to provide the daily caloric intake needed to sustain life, hand feeding provides the companionship needed to sustain the human spirit and is more affirmative of the unique and incomparable worth of every human life.

Yet, tube feeding is often the preferred choice, even when oral feeding is physiologically possible, for several reasons. For example, there may be state and/or institutional regulations regarding daily nutritional intake; limitations regarding surrogate authority to discontinue medically assisted nutrition and hydration; a limited number of staff or volunteers to do hand feeding; and, in some states, greater reimbursement rates for nursing homes that care for tube-fed rather than hand-fed residents. Of course, many patients are physically unable to take nutrition and hydration orally. In such cases, a decision to initiate or continue tube feeding must take account of the indications for its use, the expected benefits, and the risks, complications and burdens.

**Basic Clinical Considerations**

Without going too deeply into the clinical details (and thus way beyond my area of expertise), there are some important considerations that patients, families, surrogates, ethicists and staff need to keep in mind to ensure that the use of feeding tubes promotes human dignity. One such consideration is the type of tube feeding that will be used. Different types of tube feeding have distinct purposes and require different formulas for feeding; and some types are appropriate only for temporary use as a bridge therapy, while others are intended to be used permanently. For example, nasogastric and nasointestinal tube feeding is intended only for short-term use because of discomfort and the risk of sinus blockage, infection and ulceration.

Long-term or permanent feeding requires a percutaneous endoscopic gastronomy tube (a PEG tube) that is placed surgically or laparoscopically, or the surgical placement of a jejunostomy tube (J-tube). While these methods are more appropriate for long-term feeding because they deliver the nutrition and hydration directly to the stomach or intestinal tract, they too carry the real risk of clinical complications. Such complications may include surgical site irritation, leaking or infection; diarrhea; nausea; vomiting; metabolic derangement; edema; aspiration pneumonia; lung congestion or swelling of the brain. The rates of complications associated with long-term PEG and J-tubes range from 32 percent to 70 percent.

It is, of course, equally necessary to take into account the indications for tube feeding, the expected benefits and the outcomes. The use of a feeding tube is appropriate for a wide variety of indications, including when a person has an esophageal obstruction, such as from head or neck cancer; an obstruction in the upper intestinal tract; difficulty swallowing due to a neurologic impairment resulting from stroke, coma, or a persistent vegetative state; or inadequate nutritional intake due to dementia, severe illness or short bowel syndrome. The expected benefits of tube feeding include better nutrition, improved skin integrity, increased comfort and less pain, satiation of hunger or thirst, improved quality of life, decreased risk of aspiration-related pneumonia, and prolonged life.

However, some studies show that the expectations of surrogates and families are much greater than the actual outcomes related to these benefits, and that the incidence of aspiration-related pneumonia, decubiti and functional status are similar three months prior to the time tube feeding is initiated as they are three months after. Moreover, certain patient populations, such as those with advanced dementia, end-stage cancer or certain metabolic disorders, or patients who naturally lose their appetite and thirst because they are actively dying, may not experience some or any of these
benefits. Yet, the rate of feeding tubes in these patient populations remains high, partly due to the significance that families and care providers attribute to tube feeding as a symbol of their love and care.

**Conclusion**

A beginning assumption underlying this essay has been that moral medicine is good medicine, and good medicine is moral medicine. Essentially, what this means is that if medical care is to respect and promote human dignity, it must at a bare minimum be clinically sound. Accordingly, we need to remind ourselves from time to time of the possibility that a benevolent but misplaced emphasis on the symbol of our love might, in the particular case, actually interfere with respecting and promoting the dignity of those we love through the provision of clinically appropriate care.

Decision-making around the use of feeding tubes must take into account the clinical context of the circumstances in which, and the purpose for which, it is being used. Such decision-making should aim for that virtuous mean through which human dignity is best served: by providing care that avoids an insistence on useless or burdensome means of maintaining life and also avoids the withdrawal of such means with the intention of causing death (cf. Directives, Part Five, Intro.).

As a final note, one might observe that this essay has scantily mentioned the issue of tube feeding for patients in a persistent vegetative state. While this is an issue of tremendous significance insofar as it concerns how some of the most vulnerable members of society are treated, the ethical questions pertaining to tube feeding more generally are as great and varied as the circumstances and types of tube feeding. As Fr. Myles Sheehan, S.J., M.D. reminds us, the case of a person living in a persistent vegetative state is only one of many circumstances in which tube feeding is indicated, and one that is less common than others. Thus, in seeking the mean between extremes, we have a responsibility not to let the issues surrounding one fairly rare circumstance of tube feeding provide the paradigm in which we make decisions regarding tube feeding in all other circumstances.

**NOTES**

1. Regarding hand feeding versus tube feeding, see "Hand Feeding Delivers Compassionate Palliative Care," *Catholic Health World*, 24, 8 (2008), May 1.
2. Regarding these and other reasons for the use of tube feeding, even when it may not be the best clinical choice, see Gillick, MR, and Volandes, AE, "The Standard of Caring: Why Do We Still Use Feeding Tubes in Patients with Advanced Dementia?" *Journal of the American Medical Directors Association* 9 (2008): 364-367.
Managing Abnormal Pregnancies Prior to Viability

During Holy Week, a reporter from the Washington Post contacted CHA to inquire why Catholic hospitals do not perform D&Cs. He claimed to have received a call from a woman who said she had been refused such at a Catholic hospital in the Northeast. During the course of a conversation with Sr. Carol Keehan, the reporter made mention of an article that seemed to support the woman’s claim. He later emailed the article to CHA.

The article in question (“When There’s a Heartbeat: Miscarriage Management in Catholic-Owned Hospitals,” by Lori R. Freedman, Ph.D., Uta Landy, Ph.D., and Jody Steinauer, MD, MAS) appeared in the October 2008 issue of the American Journal of Public Health (Vol. 98, no. 10, pp. 1774-78). It has since been cited in a more recent article in the same journal and is summarized in the NEJM’s Journal Watch (14, no. 1, January 2009: 5).

The authors interviewed six OB-GYNs “working with and within Catholic-owned health institutions, each of whom reported at least one … event” (1776) in which the physicians were barred “from completing emergency uterine evacuation while fetal heart tones were present, even when medically indicated” (1777). The physicians claimed that in these cases, “Catholic doctrine interfered with their medical judgment” (1774). Based on these six interviews, the authors convey the impression that miscarriage management is deficient in Catholic owned-hospitals because of the institution’s moral beliefs and its “right to refuse care as granted by ‘conscience clauses’” (1778).

The authors make several misleading claims in the article. Among the more concerning are the following:

- Catholic hospitals (i.e., ethics committees) do not permit uterine evacuation so long as fetal heart sounds are present. This seems to be the chief complaint.

- “Contradictory interpretations of Directive 47 in the Catholic health literature and in practice indicate that ethics committees are either uncertain or in disagreement about how to manage miscarriage when fetal heart tones are present and what exact circumstances allow for termination of pregnancy in Catholic-owned hospitals” (1778).

Regarding the first claim, Directive 47 is the operative Directive when the fetus has not reached viability. The Directive states: “Operations, treatments, and medications that have as their direct purpose the cure of a proportionately serious pathological condition of a pregnant woman are permitted when they cannot be safely postponed until the unborn child is viable, even if they will result in the death of the unborn child” (emphasis added). Nothing is said here about having to wait until there are no “fetal heart tones” before intervening. Nor does any other authoritative source require this. In fact, Directive 47 makes no sense if clinicians must wait until the cessation of a fetal heartbeat. The very point of the Directive is to allow for an indirect abortion. It recognizes that medical interventions to address a serious pathological condition of a pregnant woman might indirectly cause the death of the fetus. Directive 47 does not require that the fetus already be dead before intervening. Where this assumption comes from is not clear, but it is not from Church teaching and it should not be from ethics committees or ethics consultants in Catholic hospitals.

The article in question refers to “the manual used by Catholic-owned hospital ethics committees to interpret the directives …” (1775). One could easily get the impression that it is this manual that prohibits any medical intervention if there are fetal heart tones. The manual that is being referred to is the one published by the National Catholic Bioethics Center (NCBC): Catholic Health Care Ethics: A Manual for Ethics Committees, edited by Peter Cataldo, Ph.D. and Albert Moraczewski, O.P., Ph.D. However, neither in the NCBC’s statement on their website on early induction of labor nor in the article on “abnormal pregnancies” in the manual...
The article in the manual reiterates the substance of this position and, again, there is no mention of fetal heart sounds. Ethics committees and ethics consultants should not be confused about this if, in fact, there is confusion.

The emotional difficulty for clinicians, however, when there are fetal heart tones, should not be minimized. There is anecdotal evidence to suggest considerable reluctance on the part of clinicians to intervene when the fetus is still alive. Such reluctance is certainly understandable. In fact, one would have reason to be concerned were it not present. But the emotional reaction to these difficult situations and decisions (i.e., the reluctance to intervene when fetal heart tones are present) is not the same as the Church’s teaching. The authors of the article got it wrong. And it is quite likely that a good number of the ethics consults in response to abnormal pregnancies result from a tension between what the Church (and Directive 47) permits and the sensibilities of clinicians.

The article makes another point, namely, that “uterine evacuation may not be approved during miscarriage by the hospital ethics committee if … the pregnant woman is not yet ill, in effect delaying care until … the pregnant woman becomes ill, or the patient is transported to a non-Catholic owned facility” (1775), and quotes the ethics committee manual’s explanation: “The mere rupture of membranes, without infection, is not serious enough to sanction interventions that will lead to the death of the child” (1775). The manual goes on to say the following:

Chorioamnionitis endangers the life of the mother and therefore constitutes a “proportionately serious pathological condition.” Hence, in Catholic facilities, preterm premature rupture of membranes calls for expectant management, unless or until chorioamnionitis supervenes. In this situation, there is virtually no chance of fetal survival and, because the mother’s life is in danger, induction of labor may be morally justified under the conditions stated above in Directive 47 (10A/2).

This statement, which accurately reflects Church teaching, rests on the absence of condition 3 in the principle of double effect, i.e., that the death of the fetus cannot be a means by which the good effect is achieved. The absence of chorioamnionitis turns an indirect abortion into a direct abortion.

Unfortunately, the article contrasts the position enunciated in the NCCB’s manual with an article that appeared in *Health Progress* (Jean deBlois and Kevin O’Rourke, “Care for the Beginning of Life: The Revised Ethical and Religious Directives Discuss Abortion, Contraception, and Assisted Reproduction,” 76, no. 7 [September-October 1995]: 36-40), characterizing the former as “conservative” and the latter as “liberal.” What the authors of the article seem to have missed in the deBlois/O’Rourke article is that the diagnosis in the case example is “probable uterine infection and threatened abortion” and they fail to understand the subsequent explanation for why the intervention in this case constitutes an indirect abortion.

In sum, the article in the *American Journal of Public Health* falsely characterizes the Church’s teaching on dealing with abnormal pregnancies as well as the general practice in Catholic hospi-
tals. While there may be occasional misunderstandings in practice or some variability in the application of Directive 47 because of the complexity of clinical circumstances and the sensibilities of clinicians, the guidance offered by the Directives is quite clear.

- The goal of any medical intervention is to save the lives of both the mother and the fetus to the extent that this is possible.

- When this is not possible, the direct purpose of the intervention should be to save the life of the woman and **not** to terminate the life of the fetus. Hence, the intervention cannot be the direct cause of the death of the fetus. This would constitute a direct abortion which is never morally permissible. However, the intervention needed to address a serious pathological condition can be the indirect cause of fetal demise.

- The woman must have a proportionately serious pathological condition.

- The intervention that would indirectly lead to fetal demise should be a last resort.

— R.H.

Key Clinical Considerations on Tube Feeding for Guiding Policy and Decision Makers in Catholic Health Care*

October 2008
Executive Summary

In response to the Papal Allocution on March 25, 2004 and the further clarification by the Congregation for the Doctrine of the Faith’s Responsum about the care and feeding of patients in a persistent vegetative state, the United States Conference of Catholic Bishops (USCCB) is currently preparing to promulgate a new revision or update for the Ethical and Religious Directives for Catholic Health Care Services (Directives), Part Five, as it relates to feeding patients. Although we do not know what the revisions will be precisely, the Supportive Care Coalition would like to offer the following clinical considerations regarding medically-assisted feeding devices (“feeding tubes”) for guiding policy and decision makers who will be charged with the practical application of the newly revised Directives.

The Supportive Care Coalition adheres to the Catholic Moral Tradition, which proscribes inappropriate termination of treatment that is a proportionate means (i.e., euthanasia) and acknowledges that under certain circumstances persons can licitly forgo treatments that are a disproportionate means (i.e., excessively burdensome with no reasonable hope of benefit.)

1. What are feeding tubes?
- There are a variety of types of feeding tubes that provide nutritional support and hydration for persons, for example, who cannot swallow.
- These tubes can be placed on a temporary or permanent basis.
- All types of feeding tubes are sometimes referred to as

* This document was prepared by a task force of the Supportive Care Coalition. It was initially shared with members of the coalition. Because of its value, we have asked permission of the Executive Director of the Coalition, Sr. Karin Dufault, if we could share the document with a broader audience.
“artificial nutrition and hydration” (ANH.)

• Nasogastric tube (i.e., through the nose, down the back of the throat and esophagus)
• Parenterally through peripheral or central intravenous lines (IV)
• PEG tubes: (percutaneous endoscopic gastrostomy tubes)
• Jejunostomy or J-tubes (i.e., below the stomach)
• Hydration alone can be provided by subcutaneous infusion

2. What are commonly perceived benefits of tube feeding?

 neflect of care, in fact, be inaccurate.
• Prevent aspiration pneumonia.
• Promote healing.
  • Improve nutritional status, which in turn is associated with reducing or preventing pressure ulcers and infections, improving functional status, and prolonging life
  • Prevent bedsores and other consequences of malnutrition.
  • Reduce incidence of post-surgical complications, infections, and length of stay
• Improve quality of life.
• Prolong survival.
• Prevent suffering.
(These perceptions and misperceptions are addressed below.)

3. What is the psycho-social context of feeding tubes?

• Because ANH is commonly viewed as a simple way to feed patients, medical professionals and the wider public in the U.S. tend to overestimate the benefits for terminal illness patients.
• Fear of pain and suffering from starvation either by patient, family, or staff lead to ANH use.
• Often times the patient is unable to make the decision.
• The reflex by families and clinicians to provide nutrition for patients who cannot swallow is overwhelming. It is now common for such patients to undergo a swallowing evaluation and if the patient fails the test, then to move forward with tube feeding placement.
• The original purpose for which ANH was developed was for temporary use but with greater frequency the purpose is permanent placement.
• The moral fallacy of the “technological imperative”—if we have it we must use it.
• Difficult to discuss, especially since the Terri Schiavo case.
• Feeding is a symbol of caring—not feeding feels like abandonment of the vulnerable.

4. When (or for whom) may feeding tubes be indicated (not exhaustive)?

• Support for patients who cannot swallow during the acute phase of neurological events like stroke or head injury and patients receiving short term critical care.
• ANH may improve the nutritional status of patients with advanced cancer who are undergoing intensive radiation therapy (e.g., obstructions due to head and neck cancer) or have proximal obstruction of the bowel (e.g., obstruction in upper intestinal tract or bowel obstruction).
• Use of parenteral ANH can prolong the lives of patients with short bowel syndrome, and prolong the survival and quality of life of patients with bulbar amyotrophic lateral sclerosis (i.e., Lou Gehrig’s Disease).
• Supplement inadequate nutritional or fluid intake arising from severe illness or failure to thrive.

5. When (or for whom) are ANH contraindicated because of the risks and complications (not exhaustive)?

Sometimes ANH is used as a means of ease and convenience because of the length of time it would require to spoon feed a patient. ANH can preserve life in some situations, but in other situations, after placement, there is substantial mortality related to underlying illness.

Examples of possible contraindications are:
• The inability to maintain nutrition though the oral route, in the setting of a chronic life-limiting illness and declining function, which is usually a marker of the dying process.
• Most dying patients do not experience hunger or thirst.
• Dry mouth is a common problem with those who are dying; however, there is no relation to hydration status and the symptoms of dry mouth.
• Numerous observational studies have demonstrated a high incidence of aspiration pneumonia in those who have been fed by nasogastric tube. This is sometimes accompanied with vomiting.
The bulk of the available evidence suggests that ANH does not improve the survival rates of patients with dementia. Some studies suggest that ANH does not improve survival rates and in comparison to spoon feeding might shorten survival rates. In short, spoon feeding might be preferred to ANH in these circumstances.

Patients with advanced dementia who receive ANH through a gastrostomy tube are likely to be physically restrained and at increased risk of aspiration pneumonia, diarrhea, gastrointestinal discomfort and problems associated with patient removing the feeding tube.

When a patient’s renal function declines in the last days of life, ANH may cause choking due to increased oral and pulmonary secretions, dyspnea (i.e., difficulty breathing) due to pulmonary edema, and abdominal discomfort due to ascites (i.e., accumulation of fluid between tissue and organs in the abdomen).

For patients who are in the last stages of dying from cancer, treating them for nutritional needs can grow their tumors and might escalate the patients' pain and suffering.

Increased risk of infection such as urinary tract, viral, gastrointestinal, and eye.

Increased risk of pressure sores.

ANH will also likely cause patients to produce more urine and stool and possible diarrhea.

Long-term placement of PEG tubes can also result in swelling of the brain.

6. Clinicians and decision-makers, especially palliative and end-of-life care specialists, need to be informed and to educate themselves about Catholic moral teaching and the Directives in this matter.

All need to incorporate relevant clinical considerations into their ethical decisions and vice versa. The Catholic Moral Tradition acknowledges that in some situations, forgoing of treatment would be morally permissible and in other situations it would be morally impermissible (i.e., euthanasia).

While every person is obligated to use ordinary means to preserve his or her life, no person should be obligated 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. The provision of food and water are, in principle, proportionate means even when delivered through a feeding tube. This means that while obligatory overall, under certain circumstances the provision of a feeding tube can nevertheless be disproportionately burdensome, especially for the dying, when it does not provide a reasonable hope of benefit or causes harm. For example, if someone is dying, feeding that person will not increase a reasonable hope of recovery or cure, and it may cause disproportionate harms including aspiration and choking, surgical complication, confusion and discomfort from being restrained to stop the patient from extubating him/herself. Or, especially invasive surgery for tube placement and its associated risks, possible restraints and tubes down the throat might constitute a grave burden in the judgment of some patients under certain conditions.

Tube feeding persons who are dying should be thought about along a continuum from simplest cases where there is broad moral agreement to the other end of the continuum with difficult cases where there is reasonable disagreement. The simplest cases are terminal patients who are known to be dying and for whom feeding would cause observable physical burdens or harms, such as a person with renal failure where feeding by any manner can promote fluid overload and respiratory distress. This case suggests that the general obligation to feed is not required in every case.

Clinicians, caregivers and others need to exercise caution when speaking of the obligation to feed persons who have a serious life-threatening illness, especially terminal patients who are dying. A poor explanation of the church’s teaching or a misapplication of the Ethical and Religious Directives can lead to unfortunate consequences.
Lead to disinformation, which would likely hamper the ability of Catholic health care ministries to collaborate with other-than-Catholic entities in mergers.

The misuse of quotes from recent papal and Vatican statements, in particular, when taken out of context of the Catholic Moral Tradition, could have a serious harmful impact on the healing mission of the church. The Supportive Care Coalitions offers this clinical background on ANH and potential impact on the mission and ministry of Catholic health care for the consideration of policy and decision makers charged with the practical application of the newly revised Directives.

NOTES


Bibliography: Ethics Committees in Long-Term Care*


*Prepared by Lori Ashmore, CHA intern.*
African American Heart Attack Patients Are Disproportionately Likely To Be Admitted To High-Mortality Hospitals
African American heart attack victims who live in racially segregated areas are disproportionately likely to be admitted to hospitals with higher-than-average mortality rates, even when the hospital closest to them has lower mortality rates, according to a new study published on March 3 on the Health Affairs Web site. The study suggests that eliminating health care disparities will likely require addressing the social factors that lead to segregation. Researchers looked at hospital admissions of Medicare enrollees for acute myocardial infarctions, or heart attacks, in 118 health care markets over the period 2000-2005. They found that blacks were 35 percent more likely than whites to be admitted to hospitals classified as “high mortality,” in which relatively high percentages of heart attack patients did not survive: 45 percent of African American patients were admitted to such hospitals, as compared to only 33 percent of white patients. (Health Affairs, March 3, 2009)

New Report Highlights Health Care System’s Financial Squeeze on Cancer Patients
Cancer patients can face severe challenges in paying for life-saving care – running up large debts, filing for personal bankruptcy and even delaying or forgoing potentially life-saving treatment – even when they have private health insurance, according to a new report by the Kaiser Family Foundation and the American Cancer Society. The report profiles 20 patients and illustrates the potential difficulties people diagnosed with cancer or other serious illnesses have in maintaining affordable health insurance and paying for their health care. (Kaiser Family Foundation, Feb. 5, 2009)

Finding a Way To Ask Doctors Tough Questions
Waiting to see his dermatologist about a skin rash, John Barnett heard the doctor sneeze loudly before he came into the exam room. The Seattle-area retiree says it took all his courage to ask, “Are you going to wash your hands before you examine me?” Despite efforts by advocacy groups and others to empower patients, challenging a doctor or nurse on whether they are correctly doing their jobs remains downright intimidating. Signs and posters in hospitals urge us to “Speak Up” if we see a potential medical error. More nurses wear buttons these days that say “Ask Me If I’ve Washed My Hands.” But even the most outspoken and assertive among us may suddenly turn meek when we are sick or vulnerable in a hospital, fearing that our treatment will suffer if we antagonize caregivers. (The Wall Street Journal, March 4, 2009)

Recession Now Hits Jobs in Health Care
Employment in health care, the only major industry outside the federal government still adding jobs, is succumbing to the recession. In the latest sign, the president of New York City Health & Hospitals Corp. wrote Friday, April 10 to community organizations as well as employees and unions at its 11 hospitals and four nursing homes, saying the agency will lay off more workers even after slashing 400 jobs last month. He blamed the job losses on state cuts in Medicaid payments to the public-health system. Across the country, hospitals are taking financial hits. They are seeing losses in the portfolios that they rely on for investment income. And with state governments continuing to cut budgets and talk of health-care reform from Washington, industry executives are preparing for even leaner times. (The Wall Street Journal, April 13, 2009)

Genetic Embryo Screening: Questions Grow Along With Number of Procedures
According to a recent article featured in the Chicago Tribune, both the number of families checking embryos for genetic defects and the number of conditions being tested are growing rapidly around the world. Determining the ethical and regulatory guidelines for such screening is proving difficult. Testing that at first focused on eliminating genetic defects certain to cause early suffering and death has expanded to defects such as genetically linked breast and ovarian cancer, which are not always fatal, hit somewhat later in life and affect 50 - 85 percent of those who carry the gene rather than 100 percent. A new study by Johns Hopkins University researchers shows that, as of 2006, 65 percent of about 200 U.S. clinics carrying out screening on embryos allowed parents to select the sex of the embryo implanted, even if the child was their first or they were not trying to create a family with a balanced number of girls and boys. That – and a recent scandal in which a California-based genetics lab advertised its ability (since disproved) to select a baby’s eye and hair color – have raised concerns among many Americans about the genetic selection of embryos. (Chicago Tribune, March 25, 2009)
Putting Muscle Behind End-of-Life Wishes

 Millions of Americans have living wills that they think provide clear instructions to medical personnel about what should and should not be done if their lives hang in the balance and they cannot speak for themselves. Yet in case after case, study after study, it seems that these documents do not result in the desired end among patients in hospitals and nursing homes. Now a new study confirms that confusion about interpreting living wills prevails in pre-hospital settings, as well. The study, conducted among 150 emergency medical technicians and paramedics by a team at Hamot Medical Center in Erie, Pa., and published in February in The Journal of Emergency Medicine, found that concern for patient safety can collide with confusion about the intent of living wills and do-not-resuscitate orders. (The New York Times, Feb. 24, 2009)

N.B.
Students from the Center for Health Law Studies at Saint Louis University School of Law contributed the following items to this column. Amy N. Sanders, Assistant Director, Center for Health Law Studies, supervised the contributions of health law students Meghan McNally (JD anticipated ’10) and Phillip Terrell (JD/MHA anticipated ’11).

Comprehensive EHR System Used By 1.5 Percent of Hospitals.
According to a report funded by the U.S. Department of Health and Human Services in The New England Journal of Medicine, 1.5 percent of non-federal U.S. hospitals use a comprehensive electronic health record (EHR) system. This does not include Veterans hospitals, which have all adopted EHR systems. If Veterans hospitals were included in the calculation, the combined total would be 2.9 percent. Ashish Jha, lead author of the report, said, “7.6 percent of hospitals have a ‘basic’ EHR that included capability to record and store physician and nursing notes” and that “10.9 percent had a very basic system” that did not include the above functions. Jha indicated that data on the effectiveness of the technologies and other forms of data sharing were unavailable, stating that “just because they have these systems doesn’t mean they are sharing that information with other doctors or hospitals down the street.” Contributing author, David Blumenthal, named by President Obama as national coordinator for health information technology, said, “IT [information technology] is one important and ultimately critical way to [support behavior change].” (Joseph Conn, Modern Healthcare, March 25, 2009)

Details of Executive Compensation Practices Released in IRS Tax Exempt Hospital Report.
In 2006, the IRS began a study about executive compensation in the country’s non-profit hospitals. The final report, IRS Exempt Organizations (TE/GE) Hospital Compliance Project Final Report, released in Feb. 2009 indicated in most cases “hospitals are following applicable laws and regulations in setting executive pay.” The report was based on responses from over 500 non-profit hospitals. Twenty nonprofit hospitals provided additional information regarding executive compensation practices. While the report does not reach specific conclusions about the appropriate community benefit standard, IRS Director of Exempt Organizations Louis Lerner indicated that he is “pretty happy” that most hospitals used comparability data when setting executive compensation.” The IRS further stated that “as discussion about the community benefit standard continues, additional information will be available as more accurate and complete data on community benefit expenditures become available through Schedule H of the Form 990.” This data is not expected to be released until late 2009. (BNA Health Law Reporter, Feb. 19, 2009.)

Collaborative Proposes Rules Engine for Interstate Transfer of Electronic Health Information
The federally sponsored Interstate Disclosure and Patient Consent Requirement Collaborative, part of the Health Information Security and Privacy Collaboration (HISPC), recommended the creation of a engine to facilitate efficient exchange of electronic health information among states. The engine will help address obstacles posed by disparate statutory and regulatory provisions governing the release of patient health records across state lines. It will operate via a set of software components to analyze a transfer request and ascertain which privacy and consent laws apply thereto. Progress is currently hampered by uncertainty and confusion regarding differences between state consent and privacy. (Government Health IT, March 5, 2009)
Physicians Pressure Medical Associations To Limit Drug Industry-Sponsored Funding

An article in the March 31 Journal of the American Medical Association by leading doctors and researchers calls for the nation's specialty medical associations to start refusing general budgetary support from drug and device manufacturers. Expressed as non-binding recommendations, the appeal suggests that associations eliminate industry-based sponsorships from almost all areas of activity except general advertising within publications and booths at trade fairs and physician conferences. “What I don't like is when I can't tell if what I'm hearing is science, or marketing in the guise of science,” said lead author David J. Rothman, professor at Columbia University in New York.

Opponents to the recommended restrictions—which previously extended to full-fledged branding on conference name tags and physician fellowship support—find that the guidelines could inhibit information received by doctors. Marjorie Powell, senior assistant general counsel for the Pharmaceutical Research and Manufacturers of America, said “Physicians are making decisions based on their scientific and medical knowledge and training.” (The Wall Street Journal, April 1, 2009)

Health and Human Services Announces Members of Comparative-Effectiveness Panel

The Department of Health and Human Services (HHS) recently announced members of the new Federal Coordinating Council for Comparative Effectiveness Research (Council), part of the Obama administration's health care reform initiatives. Council member, Carolyn Clancy, MD, director of the Agency for Healthcare Research and Quality, explained that HHS will seek recommendations concerning different treatment options, which will later be presented to patients and doctors alike as they make health care choices. This research will take place at AHRQ, the National Institutes of Health and HHS through funding from the recent stimulus bill. Other panel members include representatives from the Substance Abuse and Mental Health Services Administration, the Food and Drug Administration, the Office of Minority Health, the Centers for Disease Control and Prevention, and the HIV/AIDS Bureau at the Health Resources and Services Administration, among many others. (Modern Healthcare, March 19, 2009)

CMS Releases 2010 Medicare Advantage Reimbursement Rates

The Centers for Medicare and Medicaid Services (CMS) announced on April 6 its Medicare Advantage reimbursement schedule for next year. Private administrators of Medicare Advantage plans will see a 4-4.5 percent cut in reimbursement beginning in 2010, in accordance with the new administration's efforts to curtail higher expense associated with Medicare managed care beneficiaries (whose coverage has cost on average 14 percent more than traditional Medicare benefits). The move caught managed care plan firms by surprise as cuts in government reimbursement were not anticipated until 2011. Many plan administrators foresee modifications of cost-sharing arrangements resulting in significant increases in monthly premiums. Republicans in Congress balked at the CMS move, especially since it is being implemented alongside a cut in physician reimbursement that Congress is likely to halt later this year. (The Wall Street Journal, April 7, 2009)
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