END-OF-LIFE CARE REVISITED

Recent Debates Have Raised Some Important Foundational Questions

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A number of claims made in recent discussions about Catholic teaching and the use of life-sustaining treatments raise important and very serious theological, philosophical, and medical questions that have received almost no direct attention or examination.

Some recent forms of argument seem to deviate from established, traditional forms of Catholic argument. Yet the nature and extent of these deviations from tradition have not been apparent to most commentators. Some recent claims have been based upon oversimplified understandings of clinical and economic reality. Still other claims appear to be based upon novel philosophies of medicine that have not been made explicit. In this brief article, I make some of these questions explicit for the sake of furthering honest discussion of the ethics of life-sustaining treatments among the faithful.

INTENDING DEATH?

Claim 1: When one discontinues the use of a feeding tube in a patient who is in a persistent vegetative state (perhaps better termed “post-coma unresponsiveness”), and that person has left no advance instructions asking that this be done for a morally legitimate reason, then one must be intending that person’s death as a means of relieving his or her suffering and therefore committing euthanasia.

This form of argument has been very prominent. However, there is an underlying, unrecognized premise at the argument’s heart—that the proper moral principle by which to analyze the act of withdrawing a life-sustaining treatment is the rule of double effect. This rule has assumed an unprecedented prominence in Catholic circles in recent years, due to the influence of what has been called the “New Natural Law Theory.” According to this theory, which effectively removes ontological considerations from natural-law thinking, everyone must act for one of a small number of reasons called “basic goods,” and one may never act directly against one of these basic goods. These theorists recognize that, in real life, however, one is constantly facing choices in which one good must be sacrificed so that another can be realized.

According to this theory, one may tolerate an act that goes against a basic good (e.g., undermines respect for life or marriage) only if this bad result is an indirect, unintended side effect of acting to promote another basic good. That is to say, the rule of double effect applies in all these situations. Therefore, in a feeding tube case, the New Natural Law Theory directs the patient’s loved ones to ask themselves, “What good am I trying to accomplish here?” If they answer, “Relieving the patient’s suffering,” they will violate the rule of double effect. Since the feeding tube itself does not appear to be doing any harm, the only way to relieve the suffering of the patient is by way of making the patient dead. Therefore, it is concluded that the act is morally impermissible.

However, the story is complicated because commentators who would require feeding tubes for patients suffering from post-coma unresponsiveness are not the only ones who use the rule of double effect in this situation. Some who argue that it is permissible to withdraw feeding tubes from such patients also invoke the rule of double effect in doing so. To make the argument work, however, they are forced to conclude that the treatment is of “no benefit,” so that even the most minimal burdens caused by the feeding tube can be considered disproportionate. Of note, this
seems to entail the judgment that life itself is not a good, since the effect of the treatment (maintaining life) is judged to be of no benefit. Justifiably, this has upset orthodox Catholic sensibilities, since it seems to denigrate the value of human life.

I argue, however, that both sides of the debate are mistaken, because they have framed the problem using the wrong principle. The Catholic moral tradition has for several centuries relied upon the casuistry of withholding and withdrawing extraordinary means of care as the proper framework for analyzing such cases, not the rule of double effect. The moral theology of forgoing extraordinary means of care was developed independently of the rule of double effect and this rule was never invoked in its development or justification. Instead, the traditional understanding of forgoing extraordinary means has been based upon the principles of “physical and moral impossibility.”

These principles are based upon the understanding that although negative precepts (“Do not commit adultery”) bind absolutely, positive precepts (“Fast on Ash Wednesday”) are always limited in a finite world. They are limited by physical impossibility (what cannot be done) and so-called “moral” impossibility (that which is beyond what a reasonable person can be expected to do or to bear in carrying out a duty). The intention of a person who refrains from fasting (say, because of age or infirmity) is not to denigrate the value of penance and self-mortification; it is, rather, to say, “I have done all that the Lord requires of me, given my finite physical, psychological, social, financial, and spiritual resources. Fasting is beyond me, and I can forgo this otherwise obligatory duty.”

The forgoing of extraordinary means of care emerges from this form of moral analysis. One has a positive duty to sustain one’s life, but this duty is limited. One need not do everything conceivable to sustain one’s life. And when a person forgoes a life-sustaining treatment under this analysis, one cannot conclude that that person has the intention of causing death.

When a faithful Catholic withholds or withdraws a life-sustaining treatment, the moral object of the act, the intention-in-acting, is to forgo a treatment that is demanding more than one can reasonably be expected to bear. The intention is fulfilled when the treatment is stopped. In so doing, one foresees death following, but death is not within the scope of one’s intention. Whereas the outer limits of judgments about when this is permissible are determined by the community of believers, decisions about what is extraordinary will always depend upon the individual case—the constitution of the patient as a person integrally considered; the nature of the condition and its treatment; and the clinical, social, and economic conditions, among others.

The traditional criteria for judging that a treatment is extraordinary (i.e., morally optional) have been either that it is futile (physical impossibility) or that it is more burdensome than beneficial (moral impossibility). Burdens have included not just pain but also the broad range of physical, psychological, intellectual, financial, social, and spiritual resources of the person, including such traditional notions as horror or repugnance at the state in which one will be left by the treatment (e.g., after amputation).

Some commentators have argued that the ordinary/extraordinary means distinction is merely an application of the rule of double effect, but this is not true historically, and in fact makes no sense when applied to many situations in which there is clear consensus among the faithful that treatment would be “extraordinary” or morally optional.

One important difference is that, under the rule of double effect, only the positive and negative effects associated with the action itself count in the proportionality assessment. When this is applied to withdrawing life-sustaining treatments, this means that the only benefits and burdens that count are those bad effects caused by the withdrawal of the treatment (e.g., shortening life) and the benefits resulting from stopping the treatment (e.g., relieving pain and side effects caused by the treatment itself and capping the treatment’s costs). This sets an almost impossibly high standard. Unless death is just minutes away, the treatment itself would need to be torturous to the patient for one to view its withdrawal as a good proportionate to the bad effect of shortening something of so great a value as life itself.

However, under the analysis proposed by the extraordinary-means tradition, the burdens of the disease itself, not just the burdens of the treatment, count in the proportionality considerations. For example, Cardinal John De Lugo wrote in the 17th century that one had no obligation to prolong one’s life by dousing oneself with water if one were being burned to death and water were reasonably available, but only in a supply great enough to prolong one’s burning to death, not enough to extinguish the fire. The pain caused by
the condition itself (i.e., being on fire), which the treatment (water) only prolonged, and not just the suffering caused by water itself (which in this case is not a burden but rather a source of temporary relief) counted in the evaluation of benefits and burdens.

Many commentators who analyze cases of the withdrawal of life-sustaining treatments under the rule of double effect appear to overstate the burdens caused directly by treatments such as ventilators. This is the only way they could use this rule to justify the claim that the positive effects of withdrawal are proportionate to the negative effect of shortening life. This might work theoretically, but in real life most life-sustaining treatments do not themselves cause much suffering. Rather, they tend to relieve some symptoms and to prolong the suffering associated with the underlying condition—much like the water in Cardinal De Lugo’s case.

For example, if a patient is comatose, he or she will not feel the discomfort of having an endotracheal tube. So the directly intended good effect of stopping the ventilator cannot be the relief of the suffering caused by the ventilator. If the patient is awake, the discomfort of ventilation is often preferable to feeling the discomfort of shortness of breath. In both cases, it is generally the suffering caused by the disease, not its treatment, that constitutes the true burden. Thus, under double-effect analysis, stopping the ventilator in most cases will be euthanasia, since the aim would appear to be to relieve the patient from a state of suffering that is being prolonged by the machine. The only way this could be accomplished would be by means of making the patient dead, and so it would not be allowed.

However, according to the traditional Catholic analysis, stopping ventilator treatment in a patient dying of a painful cancer would be the morally permissible forgoing of an extraordinary means of care. The burdens of the disease count in the equation (e.g., the pain caused by the cancer). The intention is not to make the patient dead, but to stop a treatment at a point at which the burdens of the disease and its treatment are greater than what one could reasonably be expected to bear in carrying out one’s duty to preserve one’s life.

EXTRAORDINARY MEANS: WHOSE POINT OF VIEW?
According to the traditional Catholic analysis (which was developed centuries before the legal concept of substituted judgment was invented), when family members or religious superiors make a judgment for the patient, they are acting on the patient’s behalf and assuming the patient’s point of view. The tradition has never focused on the family’s motives and beliefs as the central moral concern. The proposed analysis that some are now urging changes this, however, by making the central moral question, when patients cannot speak for themselves, “What basic good is the family member attempting to realize by way of his or her act?” The Catholic tradition, by contrast, asks the family to assess whether the patient could be presumed to have met the reasonable limits of what would be necessary in carrying out his or her duty to preserve the gift of life. This difference is so subtle that it largely goes unnoticed, but in reality the shift is monumental, and changes the whole character of the analysis.

THE COST OF CARE
To complicate matters further, the way that claims about the financial costs of treatments have been bandied about in recent discussions appears to draw upon an insufficient understanding of the actual clinical and economic reality. Traditional analysis has allowed consideration of costs to enter into judgments about whether treatments are extraordinary either because (a) the patient has decided to forgo a treatment as an act of charity or (b) because the treatment is prohibitively expensive. But recent discussions seem dominated by a somewhat oversimplified understanding of the costs of certain types of treatment. Tube feeding is assumed to be cheap. However, tube feeding involves far more than the cost of the nutrient solution.

First, little attention is paid to the fact that no one ever gets to the point of being in post-coma unresponsiveness without millions of dollars having already been spent in hopes of a recovery. It takes six months of intensive care just to make the diagnosis! Second, the additional costs of caring for patients—such as special beds, nursing care, supplies, testing, pumps, electricity, hospitalizations for complications, and so forth—are never considered in discussions of the costs involved in supplying tube feeding.

On the other side of the equation, many treatments that seem more technologically sophisticated than tube feeding have become much less expensive than many commentators seem to appreciate. It has been estimated that the annual cost of feeding tube supplies for home treatment (adjusted to 2005 dollars) is about $12,000 per year. This is relatively cheap, but it does not count any costs for nursing home care (which would bring the cost to $868,000 per year), nor does it count the labor costs if treatment were given at home (estimated at $37,000 per year). This is roughly comparable to the annual cost of
continuous ambulatory peritoneal dialysis (CAPD) at home, which is about $17,000 per year for supplies; $28,000 if one includes labor, electricity, testing, and other factors. Some developing countries such as Malaysia have reduced the annual cost of the supplies for CAPD to as little as $7,000. Both tube feeding and CAPD can be done at home. Both involve placing a tube through the abdominal wall to replace a lost physiological function. Patients die in similar time frames after discontinuing dialysis or feeding tubes (about two weeks).

If one of the main arguments in favor of declaring feeding by tube to be ordinary and obligatory is its low cost relative to other treatments and relative to the wealth of developed nations, then CAPD would also have to be considered in principle ordinary and morally obligatory for all patients in renal failure, even those suffering from post-coma unresponsiveness. Similarly, ventilators can now be used at home, oxygen can be delivered via oxygen concentrators, and the price of this treatment is thought to have come down considerably from the $77,000 per year estimated in 1997. A year’s worth of antiretroviral drugs for HIV costs substantially more than this.

The point is that the church must be extremely careful about the reasoning being invoked to conclude that feeding tubes are ordinary and morally obligatory in any particular clinical circumstance. It does not seem to me that the magisterium has explicitly decided to revoke a 600-year-old tradition of moral reasoning in favor of a new method for analyzing such cases. And if this new method of analysis is used in the case of feeding tubes, the precedent-setting implications are potentially astounding, given the propensity for life-sustaining treatments to become increasingly available and less expensive relative to the economies of the developed world. A rash move in this case threatens to make Catholics servants of technology, when the point of technology ought to be its service to the human person.

**The Nature of Human Suffering**

**Claim 2A:** It cannot be argued that, if patients are in the condition of post-coma unresponsiveness, feeding tubes cause them any pain. Since, by virtue of their brain damage, such patients cannot be said to suffer from the treatment, the only intention one could have in discontinuing feeding-tube treatment would be to make them dead by way of a judgment that they are unworthy of life.

**Claim 2B:** If their feeding tubes are discontinued, patients in post-coma unresponsiveness suffer miserably from the pangs of starvation and die with parched tongues and cracked, bleeding lips. It is a cruel and inhumane to make a person suffer so.

Recent arguments about the use of feeding tubes in patients who suffer from post-coma unresponsiveness raise significant questions about the nature of suffering, the human person, and Catholic teaching. Some people, in arguing that feeding tubes are always ordinary and morally obligatory in cases of post-coma unresponsiveness, have used both of the arguments above. The arguments do not appear in the same paragraph, but have been invoked by the same source. When they are placed side by side, it is easier to see that these arguments are internally inconsistent. One cannot argue both that tube feeding must be continued because such patients lack the neurological substratum for experiencing suffering and also that tube feeding cannot be discontinued because the patients will thereby experience intense suffering.

Additionally, the clinical descriptions of such deaths are medically misguided. Most persons who die of chronic illnesses stop eating at the end of life, and dehydration is generally a contributing cause of such deaths, whether resulting from cancer or tuberculosis. While there is a tendency towards dry mouth (often exacerbated by the injudicious use of oxygen), this problem can be treated with ice chips, sips of water, or gentle mouth swabbing by nurses or family members.

Also, it is unclear whether feeding tubes help relieve the sensation of hunger. They provide no taste or smell or oral sensation, and since the nutritional solution is usually dripped into the tube continually to avoid the side effect of aspiration pneumonia, feeding tubes do not provide a sensation of satiety—the patient’s stomach is
never full. Thus, discontinuing the tube would not deprive a patient of a sensation of satiety.

Finally, the question exists whether any of these physical sensations can be cognitively appreciated by a patient who lacks function in the cortex of the brain.

But such contradictions and clinical mischaracterizations aside, these arguments raise much deeper and serious questions for Catholics about the nature of human suffering. Do we believe that a person in post-coma unresponsiveness cannot suffer? Provided that the diagnosis is relatively certain, it would seem that there could be no cognitive appreciation of such sensations as pain or thirst. But does this mean that the patient is not suffering? Certainly, in ordinary English, it would appear grammatically correct to say that a person is suffering from post-coma unresponsiveness. And no sane person would ever say that he or she wished to be in such a condition. But if a person, integrally considered, is in a state in which he or she is deprived of conscious interaction with the physical world, but not yet dead and united with the One, True, and Eternal Source of all life and all goodness—is this person not in a state of suffering?

As Pope John Paul II wrote in Salvifici Doloris:

Suffering is something which is still wider than sickness, more complex and at the same time still more deeply rooted in humanity itself. A certain idea of this problem comes to us from the distinction between physical suffering and moral suffering. This distinction is based upon the double dimension of the human being and indicates the bodily and spiritual element as the immediate or direct subject of suffering. Insofar as the words “suffering” and “pain,” can, up to a certain degree, be used as synonyms, physical suffering is present when “the body is hurting” in some way, whereas moral suffering is “pain of the soul." In fact, it is a question of pain of a spiritual nature, and not only of the “psychological” dimension of pain which accompanies both moral and physical suffering. The vastness and the many forms of moral suffering are certainly no less in number than the forms of physical suffering.

It would seem that the church, when considering the use of life-sustaining treatments in patients with post-coma unresponsiveness, must be particularly careful about making judgments that depend upon assumptions about the nature of human suffering that might narrow the field of what we, as Christians, understand about the nature of human suffering. We must, above all, never endorse the notion that any of the essential features of human beings can be reduced to brain states. Persons who suffer, suffer as persons in their totality.

**What Is a “Medical” Act?**

**Claim 3: The use of feeding tubes is an act of basic human caring, and is not a medical act.**

This argument is commonly invoked by those who would declare feeding tubes in post-coma unresponsiveness an a priori ordinary means and therefore, in principle, morally obligatory. However, one can raise serious questions about whether this line of argument can bear the freight that has been loaded upon it.

It is obvious that feeding is associated with caring, beginning with the relationship between mother and child. Eating is associated with love in the Scriptures, from the multiplication of the loaves and fishes to the post-resurrection appearances of Jesus at Emmaus and shores of Lake Tiberius. And it is clear that the emotional significance of feeding tubes, and their symbolism, make the decision to withhold or withdraw feeding tubes particularly stressful for family members, even compared with the stress of forgoing other treatments.

No one doubts that only a physician can perform a percutaneous endoscopic gastrostomy (PEG) and insert a tube to be used for feeding. In this sense, it is clearly a medical act. Some argue, however, that once the tube is in place, its use becomes nonmedical, obligatory, ordinary care.

This argument deserves more attention than has been given to it.

First, logically, this would imply that withholding a PEG tube would be morally permissible, since its insertion is a medical act, whereas discontinuing its use once it is in place would be prohibited, since its use is not a medical act. This would be the first instance of a Catholic teaching that there is a morally relevant distinction between withholding and withdrawing care. The tradition has always consistently held that the same criteria apply to withholding as apply to withdrawing life-sustaining treatments. This would be another departure from tradition.

Second, there seems to be, on the basis of this argument alone, no principled reason for distinguishing between post-coma unresponsiveness and any other clinical condition. It would seem that one ought to be prohibited from discontinuing assisted hydration and nutrition for any and
all patients if the act is not medical and represents basic human care. If this intervention is necessary in order to show respect for the dignity of the person who suffers from post-coma unresponsiveness, then it also ought to be given to other patients, who have no less dignity and are no less worthy of similar respect. This, of course, would have the absurd conclusion that no one dying of a chronic illness could have a feeding tube withdrawn.

Third, unless it is totally ad hoc, the general form of the argument being advocated here must be something like the following: that whenever a medical device has been inserted or attached to a patient, and a layperson can be trained to use it, the use of the device becomes nonmedical and in principle ordinary and morally obligatory once the procedure has been completed. Under this argument, a person who had undergone a leg amputation and the attachment of a prosthetic limb would be obliged to use that prosthetic limb and crutches even if his or her other leg were later amputated because of life-threatening gangrene. It would be wrong, according to the argument, to forgo the use of the prosthesis in order to accept life in a wheelchair. Even though, given the new condition, using a wheelchair might be much easier and would render the patient more mobile, the use of the prosthesis and crutches would be required because the use of the prosthesis had become nonmedical and morally obligatory. Such a conclusion seems odd in the light of common sense and Catholic tradition.

So perhaps the form of the argument should be modified in such a way that the medical device in question would have to be life-sustaining in order to be declared nonmedical and morally obligatory. But then support with a home ventilator would, in principle, be considered nonmedical and morally obligatory and could never be discontinued, because of life-threatening gangrene. It would be wrong, according to the argument, to forgo the use of the ventilator in order to accept life in a wheelchair. Even though, given the new condition, using a wheelchair might be much easier and would render the patient more mobile, the use of the ventilator would be required because the use of the ventilator had become nonmedical and morally obligatory. Such a conclusion seems odd in the light of common sense and Catholic tradition.

As a last resort, one might ask: What if the trached patient were able to breathe on his own—would you remove the oxygen from the room? The answer is clearly no; that would be a direct act of killing. Taking away someone's supply of oxygen is not analogous to a failure to provide food. The killing/allowing to die distinction classifies the former as killing and the latter as allowing to die.\textsuperscript{10} Taking the oxygen out of the air that a dying person is breathing is killing and is always wrong. Failing to provide food is allowing to die. Doing so is sometimes wrong and sometimes morally permissible. It is wrong not to feed a baby who can eat. It is not wrong to refrain from force-feeding someone dying of cancer who has lost his appetite.

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\textsuperscript{10} Ambu is the trademarked name of a self-reinflating bag used in resuscitation.
The proper parallel is not between air and food, but between breathing and swallowing. The analogous medico-moral issues concern the interventions aimed at assisting persons who have lost these functions. If that is so, then just as there are reasonable limits to the obligation one has to replace the lost function of breathing via a ventilator machine or an Ambu bag, there are limits to the obligation one has to replace a lost ability to swallow with a pump machine or a syringe. So there seems to be no principled way to define a medical act in such a way that feeding tubes are classified as “nonmedical” while other treatment modalities that are initiated and prescribed by physicians remain classified as “medical.”

In any event, why does this odd foray into an idiosyncratic interpretation of the philosophy of medicine require a dogmatic definition from the church? The concepts of “health,” “disease,” “therapy,” and “medicine” are also hotly debated in the philosophy of medicine. Is the answer to the medical/nonmedical question of such import that the church must define which acts are, when performed by medical personnel, in fact not medical?

Perhaps more importantly, the whole argument is irrelevant from the point of view of traditional Catholic teaching. The tradition has never considered the question of whether something was “medical” to be a criterion for distinguishing ordinary from extraordinary means of care. Very commonplace acts, such as traveling to a healthier climate, eating certain kinds of foods, or even eating itself have all been considered, in the proper circumstances, “extraordinary means” under traditional analysis. Does the church think it is important (a) to define this distinction between the medical and the nonmedical and then (b) to alter the tradition and make this a decisive factor in distinguishing ordinary from extraordinary means of care?

Does the symbolic value of a feeding tube itself carry the weight of the argument? Is the symbolic meaning of eating in the Gospels carried by the physiology of nutrient absorption, or by the interpersonal human experience we normally consider part of sharing a meal? What would the implications of such a dogmatic declaration be for our Eucharistic practices? Would we thereby say, of a person who cannot swallow but is awake and alert, that it would be preferable to deliver a small bit of the consecrated bread or wine into the feeding tube than to place a drop of the consecrated wine on the person’s tongue? Which would we consider truer to the sacramental meaning of sharing in the Body and Blood of Christ? These questions ought to be carefully considered before any formal dogmatic pronouncements are made concerning the use of feeding tubes.

**NOTES**

1. The arguments outlined in this section are presented in much greater detail in Daniel P. Sulmasy, “End of Life Care and the Rule of Double Effect: Some Clarifications and Distinctions,” *Vera Lex*, vol. 6, nos. 1 and 2, Winter, 2005.