

THREE END-OF-LIFE CASES: RESOLVING THEIR MORAL DILEMMAS

RENÉE MIRKES, OSF, PHD

An organization of Roman Catholic physicians presented a set of questions to guide moral assessment of three end-of-life cases. The questions for each scenario highlight a corresponding ethical dilemma: (Case #1) the determination of brain death by neurological criteria; (Case #2) the decision to withhold or withdraw artificial nutrition and hydration from an unresponsive wakefulness syndrome (UWS) (formerly referred to as persistent vegetative state, [PVS]) patient; and (Case #3) the administration of pain medication that hastens death. To adjudicate the moral concern raised in each of these clinical cases, the following moral analyses appeal to the natural law perspective summarized in the *Ethical & Religious Directives for Catholic Health Care Services*¹ and in other philosophical resources, both Catholic and secular.

CASE #1

An 18-year-old involved in a motorcycle accident was brought to the emergency room with massive head trauma and life support. A brain angiogram showed no blood flow, and a neurological examination revealed no brainstem reflexes as well as persistent apnea. Blood pressure medication was required for heart rate and blood pressure control. Since the patient was an organ donor, the organ recovery team was called in after he was declared brain dead.

Discussion

(1) When and how do we declare a person dead? What is the difference between theological and scientific definitions of death?

(A) A living human being is a substantial union of a (mammalian) body and a rational soul. We are not spiritual beings who use or have bodies. We *are* our bodies. Every living human being is, *at once*, an embodied person who is rationally intelligent and free.

The Christian understanding of death has always been the separation of the soul from the body. A human person dies when the soul, the formal principle of unity and integration, leaves the body, causing the gradual dis-integration or de-formation of the body. John Paul II explains that *death occurs* when the soul, the spiritual or informing principle of the body, which ensures the unity of the individual, can no longer exercise its function in and upon the organism, with the result that bodily elements, left to themselves, begin to disintegrate. When death occurs there is no longer a living human body, a person, but a cadaver, the bodily remains of a person.

Our Christian faith also affirms the fact that our soul, the spiritual form of our bodies, is immortal and therefore continues after death. “The Church proclaims its belief in the sacred continuum of life: life that is sacred, social, and eternal. Death is a natural part of this continuum. Touched by the hand of God death is a moment

of grace as an individual enters into final union with God the Creator.”² At the end of time and the final judgment, the soul will be reunited with the body, restoring the person to his original composite (body-soul) unity.

(B) The Roman Catholic Church looks to the medical community to determine the biological signs that indicate with moral certainty that the event of death has occurred. As Ethical and Religious Directive (ERD) #62 states: “The determination of death should be made by the physician or competent medical authority in accordance with responsible and commonly accepted scientific criteria.”

There are basically three ways to determine death:

- First, putrefaction (the decay or rotting of the body) and *rigor mortis* (the stiffening of the muscles of the body occurring shortly after death) are, for both medical and non-medical persons, reliable indicators that death has occurred.
- Second, the cessation of cardio-pulmonary function (permanent cessation of the beating of the heart and the functioning of the lungs) is a reliable medical indicator that death has occurred. In this case, death is determined by cardio-pulmonary criteria.
- Third, the complete and irreversible loss of all brain function is another reliable way medical professionals determine that a patient has died. Death for the comatose person on a ventilator must be determined by key neurological benchmarks. Neurological testing criteria verify whether the patient is brain dead, that is, whether the patient’s entire brain (cerebrum, cerebellum, and brain stem) is nonfunctional. If, after application of neurological testing criteria, the person’s entire brain is found to be nonfunctional, the person is declared dead.

“There is only one kind of death—when one is dead, one is dead—but death can be determined in the two different ways described in the law. A brain dead individual who is warm and pink with heart beating and lungs ventilating is just as dead, legally, as an individual whose body has turned cold after the heart has permanently stopped beating.”³

Death is a process with a timeline and cannot be envisaged as a one-time event with two dichotomous states, dead and not dead. There is a need to determine a point on the timeline of the death process that defines a point of no return after which the patient enters a rapid, irreversible course to ultimate death. Death in essence is failure of the cardio-respiratory system that transports chemical nutrients and oxygen needed for the continued life and metabolism of cells. The sensitivity of cells to oxygen deprivation varies; brain tissue is the most sensitive, and its cells will die earlier than those of other tissues. When the cardio-respiratory system fails to deliver enough oxygen and nutrients to the brain, *brain cells will die earlier than those of the heart and blood vessels, making brain death an earlier indicator of death than death of the cardiovascular and respiratory systems.* Death of the brain and its vital centers that control the respiratory and the cardiovascular systems lead to death of these two systems.⁴

(C) Two developments have necessitated the determination of death by neurological criteria.

First, the advance of intensive therapy and the ventilator in the 1950s produced a new class of patients who continued to maintain respiratory and cardiac functions but had very little or no detectable neurological activities.⁵ In other words, technological advancements in critical care have made continued circulation and respiration possible through mechanical means even after the complete brain function of the patient has ceased. Sometimes, a person on a respirator can recover full and spontaneous heart and lung function after being temporarily assisted by such machines, proving that the person's ability to function as a unified organism has not been destroyed. But in another instance, like that of the motorcycle accident (MCA) victim described here, the patient is no longer clinically alive (that is, the neurological tests showed: coma or unresponsiveness, absence of cerebral motor responses to pain in all extremities, absence of brain stem reflexes, and apnea). But his organs are being maintained by machines. In sum, the respirator is maintaining his heart and lung function even after the patient has died, that is, after the unity of the patient's bodily organism has ceased to exist.

Every hospital has a standardized set of criteria that it uses for the determination of brain death, and many hospitals also have a brain death committee that is charged with keeping up to date on the latest medical information about brain death. However, no national consensus has been reached on who is qualified to perform a brain death exam. Because it requires a thorough neurologic exam, including assessment of brainstem reflexes, most institutions utilize the expertise of a neurologist or neurosurgeon. However, critical care intensivists, with the proper training, are also capable of performing this type of exam. Careful examination of the patient is required and all areas of the brain are tested.

The brain death testing criteria used by most U.S. hospitals are based on the American Academy of Neurology's evidence-based guidelines for the determination of brain death, originally published in 1995. These consist of: (1) A *clinical exam* which checks for brain reflexes of the majority of the 12 cranial nerves, testing for cough, gag, eye movement to stimuli and touch, withdrawing to pain, etc. (the MCA victim showed "no brainstem reflexes"), and (2) an *apnea test*, to confirm or deny the loss of spontaneous respirations. Because various factors may trigger the ventilator and falsely suggest spontaneous breathing, the AAN has determined that the apnea test can be reliably performed only by disconnecting the patient from the ventilator. The patient may be taken off the ventilator for 8 minutes during which the patient's abdomen and chest are observed for movements. If no movements are seen, as in the case under consideration, a new blood gas is drawn. When the PCO₂ has reached 60 mmHg, the apnea test is positive. If the PCO₂ has not risen to the desired target range, the apnea test should be repeated for 10 minutes. If the patient takes even one breath during the 8-minute apnea test duration, he/she is determined *not* to be brain dead.

The results from the brain death testing criteria of the clinical exam and apnea test, and that from the angiogram which showed no blood flow to the brain, confirmed the MCA victim was clinically dead, though his organs were being kept alive by means of mechanical ventilation for organ donation purposes.

One organ recovery team member describes why cerebral scintigraphy or cerebral brain flow test (CBF) is the best test to confirm brain death. A CBF is a noninvasive nuclear medicine study involving I.V. administration of a radioisotope. It is widely

used because of its noninvasive and portable nature and because of its extremely reliable results. When the brain herniates, it swells and then collapses onto the brain stem and blood flow ceases. On a CBF, the lack of blood flow to the brain appears as a black hole, or what is known as “hollow skull phenomena.” A brain that is not “dead” will appear *white* due to blood flow. The results of the CBF are a powerful tool to communicate what brain death is and why the body of the MCA victim on the respirator is no longer clinically alive, but a heart-beating,⁶ lung-ventilating cadaver whose organs are being maintained by machines for organ transplantation readiness. These stringently designed criteria (neurological testing and CBF) are intended to eliminate human error and carelessness in the determination of death in persons who, like the MCA victim—intubated/ventilated as a result of a traumatic head injury—could not be declared dead by cardio-pulmonary criteria. However, brain death remains a challenging clinical diagnosis. Understanding the brain death exam process is key to making the correct diagnosis. Eliminating complicating conditions and performing a thorough neurologic exam and apnea test are important in assuring the brain death diagnosis is accurate and accepted. The confirmatory test should be performed after the neurologic exam has been completed and documented.

The second development which necessitated seeking new clinical signs of death was organ transplantation. Transplants are likely to be successful if they are retrieved from a cadaveric body through which blood (and oxygen) continues to circulate. In order for the organs to qualify for transplantation, transplant surgeons must keep the cadaver of a dead donor on a respirator to keep the organs alive (i.e., transfused with oxygenated air).

(2) What is the Church’s position on “brain death” or, better stated, death determined by neurological criteria?

In August of 2000, Pope John Paul II, addressing the question of the determination of death using neurological criteria, concluded: “The criterion adopted in more recent times for ascertaining the fact of death, namely the complete and irreversible cessation of all brain activity, if rigorously applied, does not seem to conflict with the essential elements of a sound anthropology.”

Statements from the Pontifical Academy of Life, the Pontifical Council of Healthcare Workers, and the Pontifical Academy for Sciences have all affirmed the conclusion of John Paul II on the legitimacy of the determination of death by neurological criteria. John Haas, president of the National Catholic Bioethics Center, argues that the number and common thread of these ecclesiastical statements indicates the teaching authority of the Church has “generally resolved” the question of the acceptability of relying on neurological criteria as a means for ascertaining death.

(3) Is brain death sufficient for definition of death?

Yes, see previous explanations.

(4) What is the state’s definition of death?

In 1968, Henry Beecher and the Harvard Ad Hoc Committee proposed that a person could be diagnosed as dead when there is irreversible cessation of the function of the entire brain (an irreversible coma). This status has since become known as brain death, and has been codified in the law of every state by their adoption of the Uniform Determination of Death Act (UDDA) after its promulgation in 1981:

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

The Determination of Death Rule (DDR) is neither a law nor a regulation—it is a description of an ethical norm: *an organ donor must be dead before vital organs are removed.* The President’s Commission on Death Determination supports two separate but complementary sets of criteria for organ donation after death. One is the irreversible absence of circulation and respiration (Donation after Cardiac Death, DCD), and the other is based on irreversible absence of whole brain function (Donation after Brain Death, DBD). The UDDA in combination with the DDR assures patients, families, physicians, and other health professionals, in cases like the one under consideration, that a patient who is brain dead is in fact dead, making removal of organs for life-saving transplantation legally and ethically acceptable (DBD).

Legally, all physicians are allowed to determine brain death in most U.S. states. Neurologists, neurosurgeons, and intensive care specialists may have specialized expertise. It seems reasonable to require that all physicians making a determination of brain death be intimately familiar with brain death criteria and have demonstrated competence in administering this complex examination. Brain death statutes in the United States differ by state and institution. Some U.S. state or hospital guidelines require the examiner to have certain expertise.⁷

(5) If there is uncertainty amongst healthcare team members about the proper execution of neurological testing criteria for the determination of death for a particular patient, what should the ER or ICU team members do? To what extent is an individual organ procurement team member allowed to cooperate in a case where the patient qualifies for organ donation but where there is uncertainty about the proper determination of the patient’s death?

If the neurological examination (clinical exam and apnea test) is not executed appropriately, for example, the physician performs the tests incorrectly or hastily—only checking for a few of the cranial nerves instead of all 15, or doing a 2-minute apnea test instead of the required 8-10 minute test—then, it would seem, anyone attending the case (ER or ICU) must confront the physician with the inadequacy and the need to correctly conduct the official brain death criteria like those specified on the AAN’s checklist. There is always this safety net if organ donation follows the determination of death: the organ procurement organization on the case will redo any test needed to confirm brain death if the physician did not do it correctly.⁸

(6) What is the Church’s position on organ donation?

The Catholic Church and Pope John Paul II have been enthusiastic proponents of organ donation. In 2000 JPPII reasserted his support for organ donation, calling it a “genuine act of love” and a “way of nurturing a genuine culture of life.” In a similar spirit, the Catechism of the Catholic Church asserts: “organ donation after death is a noble and meritorious act and is to be encouraged as an expression of generous solidarity.”⁹

ERD #63 calls Catholic healthcare institutions to “encourage” and “provide the means whereby those who wish to do so may arrange for the donation of their organs

and bodily tissue, for ethically legitimate purposes, so that they may be used for donation and research after death.”¹⁰

ERD #64 underlines the fact that organs may only be removed after “it has been medically determined that the patient has died.” And, to prevent conflict of interest, “the physician who determines death should not be a member of the transplant team.” This point has been made above when discussing the safety net of a second round of neurological tests by the procurement team when the attending physician’s application of the neurological testing criteria has been less than rigorous.

CASE #2

A healthy 62-year-old man develops severe epistaxis which fails to resolve with simple measures. While in the emergency room he aspirates a large blood clot and suffers cardiopulmonary arrest. By the time his airway is secured, he suffers severe anoxic brain injury. Over the next six months, his health status—opens eyes spontaneously, withdraws from pain, does not verbalize, is able to breathe independently but unable to swallow his own or oxygenated fluids—does not change. Subsequent neurology consultation and testing conclude there is no reasonable hope of recovery from his unresponsive wakefulness syndrome (UWS) (formerly referred to as persistent vegetative state, [PVS]).

His family produces his Living Will which states that he does not desire resuscitation, ventilator support, or food and hydration if he has a terminal illness or is expected to be in an unresponsive wakefulness syndrome. The family requests all IV fluids be stopped, no medication be administered, and he be “allowed to die.” In addition, the family has no insurance to cover the expenses of care in a long-term facility where his life could be prolonged indefinitely with a feeding tube.

Discussion

Decisions regarding withholding or withdrawing artificial nutrition and hydration (N&H) from an unresponsive wakefulness syndrome patient are, in my mind, some of the most complex and difficult end-of-life issues both for surrogate decision makers and healthcare providers. There is no one-rule-applies-to-all here; decisions must be in response to *this* patient in *this* very specific set of medical circumstances.

It seems to me the following spiritual/moral considerations form the warp and woof of the end-of-life decisions that surrogates are called to make, especially in situations like the case under scrutiny where familial financial burden is involved. Decisions must be: God-centered, guided by present and ultimate reality (that is, by natural and divine reason), and impelled by a spirit of loving-the-patient-to-death.

(1) Can inability to pay for long-term care be a sufficient reason for a treatment to be disproportionate?

This is what ERD #56 states: “A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden *or impose excessive expense on the family or the community*” (italics mine).

Not to split medical-moral hairs here, but the use of the coordinating conjunction “or” in ERD #56 is important in answering this question. I think the sentence under scrutiny could also read: “Proportionate means are those that in the judgment of the patient (either) (1) offer a reasonable hope of benefit and do not entail an excessive burden or (2) [do not] impose excessive expense on the family or the community.”

Understanding the directive this way, one could answer the question at hand affirmatively: Yes, the provision of N&H in this case could be considered disproportionate or extraordinary because it fulfills the second determinate for *disproportionate* care: that is, the family believes provision of N&H will “impose excessive expense” on them. This argument implies that it would be against reason to initiate or continue provision of artificial N&H if the cost of it puts the family in financial hock and constitutes imprudent community use of scarce medical resources.¹¹

The difficulty in honoring the patient’s request and the family’s concerns is that doing so would appear to contradict ERD #58: “In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the ‘persistent vegetative state’) who can reasonably be expected to live indefinitely if given such care.” Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be “excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.”

Notice the introductory phrase “in principle” of ERD #58. In principle or “in theory” usually presumes the best of circumstances and is sometimes used to contrast what happens in the real world—“in practice” (like the less-than-ideal situation of this patient) where, because of financial exigencies, things may have to be decided on practical, not theoretical, grounds.¹² Hence, given the practical constraint of excessive financial burden, one could omit the provision of N&H to the patient under consideration. However, since ERD #58 does not include the extenuating circumstance of familial financial burden but only burden to the patient, I am sure this point will provide fodder for follow-up discussion.

I should also point out in this case, as in the other two, there is plenty of room for persons of good will to variously interpret the pertinent ERDs. For example, in a Q&A from the United States Conference of Catholic Bishops (USCCB) Committee on Doctrine and Committee on Pro-Life Activities regarding “The Holy See’s Responses on Nutrition and Hydration for Patients in a ‘Vegetative State,’” the USCCB summarizes the responses of the Congregation for the Doctrine of Faith (CDF) with a series of questions and answers. To one of the USCCB’s summary questions: “May nutrition and hydration be withheld from patients in a persistent ‘vegetative state’ because prolonged care for them may involve significant costs?” came this summary answer:

No, because in technologically advanced societies the costs directly attributable to the administration of nutrition and hydration are generally not excessive. To be sure, the costs and other burdens placed on families by the patient’s need for prolonged care may become very significant. However, this real problem

must not be resolved by removing basic care so the patient will die. While one may act to reduce or remove a burden caused directly by the administration of nutrition and hydration if the benefit is not proportionate to the burden, we must not dismiss life itself as a burden even when its helpless state may call on us for other forms of care. To act to end life because life itself is seen as a burden, or imposes an obligation of care on others, would be euthanasia.

(2) Given the facts on the ground in Case #2, is the intentionality of the physician in deciding to withhold a feeding tube to directly kill the patient, or is it to withhold futile treatment and allow the patient's underlying pathology to follow its natural course?

This question is answered in the response to question three.

(3) How should the healthcare workers act when a legal document is directing them to act in a way which is contrary to their conscience (allowing a patient to literally starve/dehydrate until death occurs)?

Here I would defer to a legal expert, since I believe there are laws on the books which govern what healthcare workers may or may not do in the case of specific patient requests in legal documents such as Living Wills and Durable Power of Attorney for Health Care.

As for the Ethical and Religious Directives for Catholic Healthcare, ERD #59 is relevant to this case and to the question of whether following the patient's healthcare judgments is contrary to Catholic doctrine and, by implication, also contrary to the well-formed consciences of medical personnel assisting in this case. The directive states: "The free and informed judgment made by a competent adult patient concerning the use or withdrawal of life-sustaining procedures should always be respected and normally complied with, unless it is contrary to Catholic moral teaching."

So, if it were decided to withhold N&H from the outset, it would appear to contradict directive 58, which presumes the attending physician (or the team of doctors) have the duty to begin N&H in the case of a UWS patient like the one in Case #2, because it constitutes basic comfort care whose provision affords reasonable life-sustaining benefits to the dying patient (and is only withdrawn when proved to be excessively burdensome or futile). Hence, withholding N&H from this patient at the outset of his diagnosis of UWS would, objectively speaking (interpreting #58 strictly), be to intentionally kill the patient by starvation and dehydration.

However, looking at the medical facts of this case and reflecting back on my clinical ethics experience, I just cannot remember a UWS case where the physician's decision not to initiate N&H constituted an intentional act of murder. Rather, the physicians I observed who decided to withhold N&H from a UWS patient made that decision based on the clinical facts on the ground as they, in my estimation, reasonably interpreted them. Consistently, the physicians I observed withheld N&H because they thought it was disproportionate care, and therefore that it merely, and unnecessarily, prolonged the patient's dying process and (as one physician commented) sadly delayed the patient from entering eternal life, the very end for which the patient had been created. In other words, the physicians I observed who did not start a feeding tube with their UWS patient were withholding N&H not with the intent to end the patient's life but to allow the patient to die of the natural cause of cardiopulmonary

arrest or cancer or traumatic head injury, whatever the underlying terminal pathology happened to be. And, in these cases, the underlying disease, not the doctor, killed the patient. The death or the hastening of the patient's death was *praeter intentionem* or *per accidens*: the unintended effect of the doctor's intentional act of allowing the patient to die.

The assisting medical personnel who honors or cooperates with a doctor whose *intent* in withholding the basic comfort care of a feeding tube is *to kill* the patient would, in my opinion, be formally cooperating in the evil of murder. However, in the case where the physician intentionally withholds N&H to allow the underlying disease process to take its course (or so as not to needlessly prolong the dying process by using futile or excessively burdensome care), the assisting medical personnel would not be formally (intentionally) cooperating in an act of murder at all but intentionally participating in an act of solidarity with the patient—swabbing the patient's mouth to keep it moist, keeping the patient as comfortable as possible, wiping the patient's face with a cool washcloth, and keeping his bed linens clean—until God comes to take him to Himself.

The question is: Will the assisting personnel necessarily be privy to the intentionality of the physician's act of withholding N&H from a UWS patient? And to introduce another twist: What if the physician makes known that he is withholding N&H to allow the patient to die, but a medical assistant in the case thinks that the medical facts on the ground dictate the doctor's intent can only be to kill the patient? Then, it seems to me, the only recourse for that medical assistant is to ask to be taken off the case and to report the assistant's assessment of the doctor's decisions to proper authorities.

The same moral description of the act of withdrawing N&H would hold true. If the physician intends to withdraw N&H to kill the patient, to directly end the patient's life, the act is morally wrong, and gravely so. But if what the physician intends to do in withdrawing N&H is to allow the underlying disease processes to take their natural course (to prevent the prolongation of the patient's dying process and the delay of the patient's beatific vision), the act is morally licit (and the death of the patient is outside of the doctor's intention).

CASE #3

A 10-year-old child suffers from an incurable rhabdomyosarcoma of the nose that eventually extends to her eyes, blinding her completely, filling the nose and oral cavity. She somehow survives the intracranial extension, and the question arises as to whether she should pursue a tracheotomy and feeding tube. She requires large doses of pain medication, but her pain remains difficult to control. There is no hope of cure for this tumor. She can no longer swallow and has trouble breathing around the tumor. On one hand she would live longer with the tracheotomy and feeding tube, but her life would be prolonged with more pain and suffering. Her family requests larger doses of pain medication, with some members requesting doses which will "take away her suffering forever."¹³ A consulting oncologist has ordered pain medication with a huge dosage range clearly allowing for palliation doses that may hasten the child's death.

Discussion

An appropriate backdrop for the discussion of Case #3 is the following excerpt taken from the article, “Killing the pain not the patient: palliative care vs assisted suicide.”¹⁴

Assisted Suicide vs. Pain Control

In important ways, assisted suicide and good palliative care are not only distinct—they are radically opposed to each other. Consider the following:

*Control of pain and suffering eliminates the demand for assisted suicide. As Dr. Herbert Hendin notes in his 1997 book *Seduced by Death*, some terminally ill patients have suicidal thoughts, but “these patients usually respond well to treatment for depressive illness and pain medication and are then grateful to be alive.” Such treatment responds to the underlying reasons why patients ask for death, instead of treating the patient himself as the problem to be eliminated. When pain control and other care improves, assisted suicide becomes largely irrelevant.*

***Assisted suicide undermines good pain management.** During the Supreme Court’s January 1997 oral arguments on its assisted suicide cases, Justice Stephen Breyer noted a remarkable fact from a report by the British parliament’s House of Lords: The Netherlands, which has allowed assisted suicide and euthanasia for years, had only three hospices nationwide, while Great Britain, which bans these practices, had 185 hospices. He had placed his finger on one of the most insidious effects of legalization: Once the “quick and easy” solution of assisted suicide is accepted in a society, doctors lose the incentive to pursue more difficult but life-affirming ways of truly caring for patients close to death. The converse is also true: prohibiting assisted suicide sets a clear limit to doctors’ options so they can commit themselves to the challenges of accompanying patients through their last days. As one physician said after years practicing hospice medicine: “Only because I knew that I could not and would not kill my patients was I able to enter most fully and intimately into caring for them as they lay dying” (quoted in Leon Kass, “Why Doctors Must Not Kill,” *Commonweal*, Sept. 1992, p. 9).*

The assisted suicide movement is willing to discredit modern pain control to advance its own cause. Euthanasia advocates know that when they equate assisted suicide and modern pain management, they are not just elevating the status of assisted suicide—among people who oppose direct killing of the innocent, they are undermining good pain control. They do not seem to care that their arguments will make doctors and patients more distrustful of legitimate practices that can truly help people live with dignity in their last days.

But strong voices are being raised to make sure they do not get away with this. In an April 1997 report on constitutional arguments about assisted suicide, the prestigious New York State Task Force on Life and the Law urged people on all sides of the assisted suicide issue to keep important distinctions clear. Noting that “many physicians would sooner give up their allegiance to adequate pain control than their opposition to assisted suicide and euthanasia,” the Task Force warned that “characterizing the provision of pain relief as a form of euthanasia may well lead to an increase in needless suffering at the end of life.”

This warning is even being raised by some who do not oppose physician-assisted suicide in principle. “Clinicians must believe, to some degree, in a form of the principle of double effect in order to provide optimal symptom relief at the end of life,” writes Dr. Howard Brody in the April 1998 *Minnesota Law Review*. Dr. Brody does not oppose assisted suicide in all cases, but he knows that many doctors do—and he knows they will not practice good palliative care if it is seen as tantamount to euthanasia. “A serious assault on the logic of the principle of double effect,” he writes, “could do major violence to the (already reluctant and ill-informed) commitment of most physicians to the goals of palliative care and hospice.”

(1) Do the family and the attending physician have a moral duty to prolong the child’s life by the insertion of a feeding tube and tracheotomy? Or could such interventions be considered extraordinary because the burden of prolonged suffering from unmanageable pain outweighs the benefit of being able to breathe and eat?

See the answer to question #2 for an explanation of when the trach and feeding tube could be considered extraordinary or disproportionate treatment.

(2) Can “quality of life” or persistent suffering cause a treatment to be considered disproportionate?

To understand whether the trach and feeding tube are disproportionate medical interventions for this child, one has to weigh the burdens versus the benefits of introducing them. Since persistent suffering and discomfort from unmanaged pain from the cancer would continue after introduction of the trach and feeding tube, and perhaps even increase, the patient’s persistent suffering definitely belongs on the burden side of the Burden versus Benefit consideration. Depending on what the family/physician counts as benefits to the child from the trach and feeding tube, the persistent suffering from the cancer and ancillary discomfiting complications from trach and g-tube (infection, pain, diarrhea, care assistance) might constitute excessive burden or futile treatment in comparison. Should this be the conclusion of the B/B analysis, the surgical placement of a trach and feeding tube could be considered disproportionate and the family/physician would not be morally obligated to introduce them. Not doing the trach or inserting the g-tube and continuing to titrate the dosage of morphine or dilaudid until the child no longer exhibits symptoms of pain would not be intentionally killing the child but intentionally treating the pain, thereby allowing, rather than unnecessarily prolonging, the child’s natural dying process.

(3) As long as the intentionality of the physician’s act of providing palliative care is to relieve pain (rather than to kill the patient), can higher doses of pain medication be used, knowing that this could cause respiratory arrest?

Yes, because the intentionality of the act (what the doctor intends both as a means and as an end, i.e., the moral object of the act) is *to provide higher doses of opioids* (the means) *to relieve the child’s pain* (the end). Respiratory arrest, unconsciousness, and a hastening of death, if they occur, are *praeter intentionem*, unintended consequences of the physician’s intentional act of providing higher doses of pain killers to relieve the child’s pain and suffering.

It is worth recalling a relevant statement from Pope Pius XII. A group of physicians asked him: “Is the removal of pain and consciousness by means of narcotics . . . permitted by religion and morality to both doctor and patient even at the approach of death and if one foresees that the use of narcotics will shorten life?” To which the pope replied: “Yes, provided that no other means exist and if, in the given circumstances, the action does not prevent the carrying out of other moral and religious duties . . . death is by no means intended or sought, although the risk of it is being incurred for a good reason; the only intention is to diminish pain effectively by use of the painkillers available to medical science.”¹⁵

Therefore, in the case under scrutiny, a higher dose of pain medication may be given to the child even though it suppresses her breathing, causes unconsciousness, and could hasten her death. These side effects of the analgesics would not be what the physician intends but what are *praeter intentionem*, that is, outside of, or accidental to, the intent of the attending oncologist or palliative doctor.

Pope John Paul II reiterated the teaching of Pope Pius XII on the use of palliative drugs for dying patients who are in pain or distress: “In such a case (use of painkillers and sedatives), death is not willed or sought, even though for reasonable motives one runs the risk of it: there is simply a desire to ease pain effectively by using the analgesics which medicine provides.”¹⁶

The Catechism of the Catholic Church (CCC) affirms that “those whose lives are diminished or weakened deserve special respect” (2276). As such, the Catechism describes palliative care as a “special form of disinterested charity [that] should be encouraged” (2279). ERD #61 confirms the CCC’s insight: “Patients should be kept as free of pain as possible so that they may die comfortably and with dignity, and in the place where they wish to die. Since a person has the right¹⁷ to prepare for his or her death while fully conscious, he or she should not be deprived of consciousness without a compelling reason. Medicines capable of alleviating or suppressing pain may be given to a dying person, even if this therapy may indirectly shorten the person’s life so long as the intent is not to hasten death. . . .” I have witnessed clinical cases where, before the dying persons are given doses of morphine to control their pain that will make them unconscious, they have an opportunity to hold the hands of, say good-bye to, and make peace with their family. Certainly, this opportunity would be of great comfort to both the child described here and her family and, hopefully, even provide the possibility for the child to die in her parents’ arms.

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

From this definition we see the intention of palliative care is neither to hasten nor to delay death but *to acknowledge that dying is a normal process*. It is widely recognized that the provision of pain medication is ethically and professionally acceptable even when the treatment may hasten the patient’s death. Health care professionals should seek to minimize this risk, consistent with adequate treatment for pain and other symptoms. Even if significant risk remains, the benefits of effective palliative care outweigh that risk.

Only after one has fulfilled

- *the first criterion of the Principle of Double Effect [The act itself must be morally good or at least indifferent.]* as we have done here in Case #3, viz., demonstrating the goodness of the intentional act of *administering palliative care to relieve the child's pain*, can one use the principle's other criteria to verify that conclusion.
- *criterion #2: [The agent may not positively will the bad effect but may merely permit it.]* The doctor intends (i.e., wills) the good effect of administering palliative care to alleviate the child's pain and discomfort but does not intend the bad effect of the child's death. As the unintended consequence of the doctor's good act of relieving pain and allowing death to take its natural course, the child's death lies outside of, or is accidental to, the doctor's intent.
- *criterion #3: [The good effect must be produced directly by the action, not by the bad effect.]* The doctor does not choose to intentionally kill the child as the means of relieving the child's pain; the doctor chooses to give pain medication as the good or reasonable means of relieving the child's suffering;¹⁸ and
- *criterion #4: [The good effect must be sufficiently desirable to compensate for allowance of the bad effect.]* The doctor considers relief of the child's agonizing pain and discomfort a proportionately serious reason to tolerate the bad effects of respiratory suppression, unconsciousness, and death.

Endnotes

1. The Fifth Edition of the *Ethical and Religious Directives for Catholic Health Care Services* (ERDs) was issued by the United States Conference of Catholic Bishops on November 17th, 2009. The Preamble to the ERDs affirms the ethics standards of behavior in health care "flow from the Church's teaching about the dignity of the human person." The moral teachings professed in the ERDs "flow principally from the natural law, understood in the light of the revelation Christ has entrusted to his Church. From this source the Church has derived its understanding of the nature of the human person, of human acts, and of the goals that shape human activity."
2. Pastoral Letter from the Roman Catholic Bishops of Wisconsin on End of Life Decisions, *Now and at the Hour of our Death*, 2006.
3. J S C Med Assoc. 2011 Aug; 107(4): 146–149. "Brain Death, Cardiac Death, and the Dead Donor Rule" Robert M. Sade, M.D.
4. *Journal of Taibah University Medical Sciences*, Vol 8, Issue 1, 2013:1-6, "Brain Death: Criteria, Signs, and Tests," Omar Hasan Kasule.
5. *When someone is brain dead, there is no blood flow or oxygen to their brain. The brain (including the brain stem which controls breathing) has ceased functioning in any capacity. Because the ventilator is breathing for the person, the organs such as the heart and liver continue to receive oxygen and are able to function for a few days after the brain has died. Unless damaged by injury or disease, the organs may be donated to another individual for an organ transplant.*
6. *The heart has its own pacemaker independent of the brain. As long as it has oxygen, as it does in the ventilated MCA victim, it continues to beat. The heart could actually be removed from the body, placed in saline solution, given oxygen, and still continue to beat. This is why although the MCA victim's brain was dead, his heart continued to beat.*
7. <http://surgery.med.miami.edu/laora/clinical-operations/brain-death-diagnosis>
8. This link [<http://www.neurology.org/content/74/23/1911abstract>] discusses the accuracy of the brain death testing when done appropriately and in full accord with AAN standards. This site and others show that when the neurological testing is done according to these guidelines, there is no

- evidence of a person “coming back to life” from brain death.
9. CCC 2296
 10. This directive raises an ancillary ethical issue. We presume that organ/tissue donation is solely for transplantation purposes, but forget it may also be used for research. Specifying that one’s donated organ/tissue be only used for morally legitimate research is extremely important. I defer the question of whether donor cards allow for those personal ethical specifications to a legal expert.
 11. The attending physician is the best person to answer the family’s questions so they can understand just what the cost of artificially feeding and hydrating a patient entails. Is artificially administered N&H of itself that expensive, or does unreasonable financial burden come from the patient’s prolonged stay in the hospital? Could the patient be sent home with artificial N&H so a family member could be taught to manage his feeding tube? Is that a real solution to the “financial burden” question when a family member might have to quit his job to be at the patient’s bedside 24/7 or when a home health nurse would need to be brought in?
 12. Additional costs might come from treating the potential complications of PEG insertion, wound infection, and diarrhea and its associated skin breakdown that often accompanies tube feeding.
 13. One can only speculate as to the meaning of the family member’s remark, “to take away her suffering forever.” Perhaps one would need to be in the situation to really know what the individual meant. Intuition dictates it is more about a family member—who, no doubt, is vicariously experiencing the child’s agony—wanting enough medication to stop the child’s pain and suffering (enabling her to die with the true dignity of loving support from medical staff and family) and less about asking the doctor to use pain meds as a means of euthanizing the child.
 14. Richard M. Doerflinger and Carlos F. Gomez, MD, PhD. For the entire article Cf: [<http://www.usccb.org/about/pro-life-activities/respect-life-program/killing-the-pain.cfm>]
 15. See Pope Pius XII, “Answer to questions on Reanimation addressed to ‘Gregory Mendel’ Institute of Genetics, 24-11-1957,” *Acta Apostolicae Sedis*, 49(1957), 1027-33.
 16. CCC 65.
 17. The International Pain Summit of the International Association of the Study of Pain (comprising IASP representatives from Chapters in 64 countries plus members in 130 countries), as well as members of the community, have given in-depth attention to the unrelieved pain in the world and agree that *access to pain management is a fundamental human right. Appropriate assessment* includes recording the results of assessment (e.g., pain as the “5th vital sign,” can focus attention on unrelieved pain, triggering appropriate treatment interventions and adjustments).
 18. *Appropriate treatment* includes access to pain medications, including opioids and other essential medications for pain, and best-practice interdisciplinary and integrative nonpharmacological therapies, with access to professionals skilled in the safe and effective use of these medicines and treatments and supported by health policies, legal frameworks, and procedures to assure such access and prevent inappropriate use. *Given the lack of adequately trained health professionals, this will require providing educational programs regarding pain assessment and treatment in all of the health care professions and programs within the community for community care workers delivering pain care. It also includes establishment of programs in pain medicine for the education of specialist physicians in pain medicine and palliative medicine. Accreditation policies to assure appropriate standards of training and care should also be established.*

Renée Mirkes, OSF, PhD, is a member of the Franciscan Sisters of Christian Charity and directs the Center for NaProEthics, the ethics division of the Pope Paul VI Institute for the Study of Human Reproduction, Omaha, Nebraska, USA.