The Value of Life and its Bearing on Three Issues of Medical Ethics

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THIS PAPER WILL address three related questions of medical morality. First, what are we to make of arguments favoring assisted suicide? Second, how should we determine when, if ever, it is permissible to withhold, or withdraw, nutrition and hydration? Third, how ought we to determine when, if ever, it is permissible to induce the labor of a pregnant woman whose fetus is not yet viable? I will examine some of the problematic ways in which certain ethicists have addressed these issues in an effort to establish by contrast the principles necessary to deal with them properly. It will become evident that we should not only exclude all directly intended death but also carefully apply the principle of double effect in a way to exclude wrongly accepting death as a side effect. It will likewise become clear that one's position on the three issues at stake will depend on whether one regards human life as intrinsically or only instrumentally valuable, and whether one has a dualistic or an integralist view of the human person.

PHYSICIAN-ASSISTED SUICIDE

Before we consider physician-assisted suicide (PAS), we must distinguish it from a choice to use pain-relieving drugs that will have the side effect of ending the patient's life earlier than otherwise would have been the case. As the 1995 papal encyclical *Evangelium Vitae* makes clear, under certain circumstances the latter sort of choice is licit. Such medication may be used only if there is no other medication adequate to deal with the patient's intense pain that will not have the additional effect of hastening his death and if the patient has fulfilled all outstanding responsibilities, such as making a will and, especially, preparing spiritually for death. Under those circumstances the patient's earlier death can be accepted as a side effect of a legitimate effort to relieve pain. PAS,

on the other hand, carries out a decision precisely to end the patient's life, generally as a means to ending suffering or removing the burdens his continued living imposes on others. With PAS, the drug used need not have any capacity to relieve pain other than by killing the patient.

Although the external behavior may be the same in the two cases, both the acts themselves and the attitude toward life they reflect are different. In the former case, the patient's life is recognized as intrinsically good and therefore worth living, despite the patient's inability to participate in the full range of human goods and the consequent emotional unattractiveness of staying alive. The hastening of the patient's death is accepted reluctantly as a side effect of using a medication designed specifically to relieve pain. In the latter case, the patient's life is treated as a mere instrumental good. When suffering increases and life no longer seems to serve as the condition for participating in *other* goods, it is presumed to be without value and therefore not worth living. The patient's life is considered expendable; the intention is to kill, and, morally speaking, there is no difference between intentionally prescribing an overdose of painkillers and suffocating the patient with a plastic bag.

It is important to note that despite the possibility that the external behavior may be the same, the acts discussed above are different because they are characterized by different proximate intentions. The agent's proximate intention shapes each human act and determines what that act is. The proximate intention is to be distinguished from the remote intention, which is the purpose the agent has for doing what he does. In both of the cases considered above, the purpose of the act is to relieve pain, but the different proximate intentions that shape the acts themselves make them specifically distinct in a morally significant way.

Sometimes those who support PAS disclaim the proximate intention and describe the act solely in terms of the agent's remote intention: to relieve suffering. They deny that PAS involves intentionally killing the patient and insist that it simply ends the patient's suffering. That is, some PAS supporters deny that PAS carries out a choice to end the patient's life as a *means* of ending his suffering, and describe the act exclusively in terms of stopping suffering. For example, at the trial in which he was convicted of murder, Jack Kevorkian told Judge Jessica Cooper: "My

intent is not to kill. But it is my duty as a physician to ease suffering. My intent is tailored towards their ultimate goal, which some people call murder, some call assisted suicide."

The claim that those who practice PAS do not seek death but only to end suffering is belied by two closely related considerations. First, there are almost always ways to end suffering without killing the patient. When such means are passed over in favor of lethal means, death is clearly intended. Second, it is hard to see how death would not be intended when the means chosen to end pain could never do so without bringing about the death of the patient. Many supporters of PAS overlook the significance of these points because they think of life as only instrumentally good and therefore do not hold that the death of a human person is always bad. They regard life as no longer worth living if it cannot serve as the condition for one's participating in other goods. As a result, though they may continue to deny that PAS means intentionally killing the patient, they see no moral problem with choosing to end such a life as a means of ending pain and removing burdens on society.

Of course, some who hold that the death of a human person is always bad nevertheless argue that PAS is sometimes morally acceptable, namely, whenever death is a lesser evil than the patient's continuing to suffer and/or the other bad consequences of keeping him alive. Some who argue in this way for the moral acceptability of PAS claim that when it is justified, death is not intended; others admit that it is intended but claim that that intention can be morally upright. Despite this difference, all such views are instances of proportionalist or consequentialist reasoning. These approaches have been subjected to cogent philosophical criticism and rejected by the Catholic Church.iii It is worth noting that some who have adopted a version of consequentialism or proportionalism have argued that PAS is not morally acceptable. But their general theory excludes exceptionless moral norms, for they insist that all concrete factors must be weighed before judging the morality of particular choices. Hence, their arguments against PAS are merely prudential rather than principled and are inevitably open to exception.

Other ethicists, however, who oppose intentional killing on principle and reject every form of consequentialism and proportionalism, nevertheless seem to support intentional killing in certain cases, or at least unwittingly support accepting death as a side effect in cases in which doing so cannot be morally justified. This will become clear as we examine the issue of withholding or withdrawing artificial nutrition and hydration (ANH).

ARTIFICIAL NUTRITION AND HYDRATION

United States federal courts have treated legal issues concerning PAS. The Second Circuit Court of Appeals claimed that "New York law does not treat equally all competent persons who are in the final stages of fatal illness and wish to hasten their deaths." The court was concerned that

those in the final stages of terminal illness who are on life support systems are allowed to hasten their deaths by directing the removal of such systems; but those who are similarly situated, except for the previous attachment of life sustaining equipment, are not allowed to hasten death by self administering prescribed drugs.

This analysis treats PAS no differently from withdrawing burdensome treatment since both involve a person's doing something that results in death. Indeed, the court states that the "ending of life by [withdrawing life support systems] is nothing more nor less than assisted suicide." This assessment ignores the significance of the means used and the agent's proximate intention shaping the act, and considers only the outward performance and the goal sought. The court reasons that by approving the withdrawal of burdensome treatment, society already has accepted PAS and should make that acceptance explicit as a standard for law. Vii

The Ninth Circuit Court of Appeals is even more explicit in its rejection of the significance of the proximate intention. It explains that according to the principle of double effect, "it is sometimes morally justifiable to cause evil in the pursuit of good" and interprets such causation as including intention. The court argues that when a doctor authorizes the disconnection of a respirator, "there can be no doubt that in such instances the doctor intends that, as the result of his action, the patient will die an earlier death than he otherwise would." The court

further states that "[i]n the case of 'double effect' we excuse the act or, to put it more accurately, we find the act acceptable,...because the act is medically and ethically appropriate even though the result—the patient's death—is both foreseeable and intended."

Kevin O'Rourke, O.P., opposes PAS and exposes the flawed moral reasoning behind the two federal appellate court rulings—subsequently overturned by the Supreme Court—that declared PAS legal. He rightly insists that the courts are wrong to

allow a good remote intention to justify an evil proximate intention. Killing an innocent person is never an ethically acceptable remote or proximate intention. Human life is a basic good, and we should never directly act in opposition to basic goods. Even though a remote intention to avoid ineffective therapy or to eliminate suffering is acceptable, this should not be accomplished by a proximate intention of directly hastening death or assisting suicide. ix

So far, I agree with O'Rourke; the principles he sets out are sound. But problems arise because, despite his statement that "human life is a basic good," he fails to treat it as intrinsically good. That failure, along with a consequent misapplication of the principle of double effect, leads him to defend withdrawing ANH from patients in the persistent or permanent vegetative state (PVS)^x even in the absence of a special circumstance. O'Rourke denies that such a decision is tantamount to PAS. He argues that "in the case of PVS, AH&N is an ineffective therapy for the pathology which causes the permanently comatose condition and it is burdensome as well. The proximate and remote intention would not be to kill the patient."^{xi} This argument is unsound for the following reasons.

First, ANH is not intended as a therapy for the pathology and should not be judged as ineffective because it does not remedy it. Its efficacy should be judged according to whether or not it really does serve to keep the patient alive by providing food and water, which it almost always does. Why does O'Rourke hold that ANH can only be justified if it remedies the pathology? He assumes that it is pointless to sustain a life burdened with the pathology that makes one a PVS patient. That assumption presupposes the further assumption that bodily life is not a

value in and of itself. So, O'Rourke considers ANH inefficacious if it merely sustains bodily life apart from what he recognizes as beneficial to the patient. Thus, to justify withdrawing ANH from one's parent in PVS, O'Rourke says: "given the physiological condition of mom or dad, we cannot do anything beneficial for them." On this basis, O'Rourke thinks that an intervention that does not resolve the underlying problem is futile. He fails to recognize that bodily life is intrinsically valuable; he regards it only as instrumentally valuable and considers it worthwhile only insofar as it enables a person to participate in other goods.

Second, the burdens of ANH are one thing and the burdens of all the other elements of the patient's care are quite another, and the two should not be confused. To remove a patient's feeding tube in order to avoid other burdens, such as the burden of keeping him clean and properly positioned in bed, is not to accept the patient's death as a side effect but to choose the patient's death as a means of avoiding those other burdens. When ANH is readily available at reasonable cost, as it is in developed countries, and when providing it does not trouble the patient, as it clearly does not in the case of a PVS patient, then the claim that the burden of ANH is excessive implies that preserving his life is of no benefit to the patient. The underlying assumption, again, is that life is not an intrinsic good but is good and worth living only if it enables the patient to participate in other goods. xiii

O'Rourke holds that there is no point in sustaining life unless doing so helps a person "strive for the purpose of life," which, "as described in the Catechism of the Catholic Church (I.1), is to know and love God." In order to pursue this purpose, "either a person must possess this capacity for cognitive-affective function or have the potential to develop this capacity." And he argues that the PVS patient lacks both the capacity and any possibility of developing it. xiv However, his conception of knowing and loving God is very narrowly drawn. Catholic pastoral practice treats those who apparently do not have that capacity or potential as apt recipients of the sacraments. Just as the severely retarded are regularly baptized, so also PVS patients, like patients in a coma and on the verge of death, are apt recipients of Baptism, Confirmation, and the Sacrament of the Sick. This pastoral practice presupposes that the relationship these

recipients have with God can be affected by receiving these sacraments. Moreover, to agree that the purpose of life is to know and love God does not entail holding either that fundamental human goods, including the good of bodily life itself, lack intrinsic value or that the purpose of life does not include participating in those goods.

The line of reasoning O'Rourke proposes—that providing medical care to sustain the life of patients is useless and burdensome if it does not help them pursue the purpose of knowing and loving God—leads to implausible conclusions when applied to other situations. William May points out that "an infant suffering from Trisomy 13 will never be able to pursue the spiritual goal of life. Yet if such an infant should suffer a cut artery it would surely not be 'extraordinary' treatment to stop the bleeding, although doing so would be 'ineffective' in helping the infant pursue the spiritual goal of life."xv

Against the position O'Rourke defends, I maintain that there are four reasons why ANH ordinarily should be provided to PVS patients.

First, ANH offers the benefit of warding off starvation and dehydration. In and of itself, sustaining the life of the patient is a benefit because human life is intrinsically, not only instrumentally, good.

Second, besides benefiting the patient by sustaining his life, ANH benefits both patient and caregiver with respect to the good of human solidarity. The very effort to sustain the life of another creates a bond that is beneficial to both parties. As many family members who have had the experience of caring for their loved ones with debilitating afflictions such as PVS have attested, conscientious caregivers enter into solidarity with the patients for whom they assume the burden of care. Caregivers with the gift of Christian faith who are motivated by charity can grow in holiness by treating the PVS patient as they would treat Christ himself and by uniting the sacrifices they make with his sacrificial passion and death. PVS patients also benefit from this care by sharing more profoundly in human community and in the community of faith. That is true, even assuming such patients have no conscious experience of that benefit. Just as we rightly say that a PVS patient suffers indignities when treated as a mere object-as, for example, when a female PVS patient is wronged by being raped—so also we rightly conclude that such a patient shares in the benefits of human community when treated with the respect due all human persons. Indeed, caregivers who conscientiously strive to ensure that Catholic PVS patients receive the Sacrament of the Sick implicitly acknowledge that the condition of such patients does not preclude their benefiting from goods other than that of bodily life itself.

Third, all competent physicians realize that diagnosing PVS is very difficult, if possible at all. The common view is that it can be diagnosed only when a condition of unresponsiveness continues for months or perhaps years. But some physicians have become convinced that it is impossible to diagnose PVS definitively. They argue that one cannot be sure that a patient has no conscious awareness whatever and will never emerge from that presumed state. ^{xvi} This difference of opinion grounds a reasonable doubt about the actual condition of so-called PVS patients. So, even those who think that only conscious life is worth living cannot reasonably maintain that ANH is useless for such patients.

Fourth, ANH generally imposes no significant burdens. The usual procedures required to initiate and maintain it are simple. Neither the nasogastric tube with smaller dimensions, which allows for non-operative access, nor the gastronomy tube, which often allows for operative access on an outpatient basis, are very costly. Moreover, the patient is either unconscious and therefore feels no pain, or the patient is conscious, in which case any discomfort caused by ANH hardly would exceed the excruciating pain of starving to death or dying of dehydration.

When, if ever, it is permissible to withhold or withdraw ANH from PVS patients? Any of three special circumstances can justify such a decision.

First, ANH obviously is not required if it is ineffective. For example, if a PVS patient cannot assimilate the nutrients provided, ANH is not providing the benefit of sustaining life and is therefore pointless. Despite a possible emotional motivation to continue ANH, human solidarity with such a patient is served by withdrawing it.

Second, it is conceivable—for example, in undeveloped countries—that ANH is out of the reasonable financial reach of some people. Those who cannot provide someone with ANH without using resources needed to fulfill other exigent responsibilities may not be morally required to

provide it. Likewise, those in charge of health care and public officials generally in undeveloped countries could reasonably decide to allocate their very limited resources to patients with better prospects than those for whom ANH otherwise would be morally required. Of course, as I explained previously, the cost of providing ANH must be not be confused with the entire cost of patient care so as to facilitate rationalizing the intentional killing of patients. xvii

Third, the patient may decide, by means of some form of advance directive, to forgo all care so that the resources that would have been expended in providing ANH may be used for other purposes. One can reach such a decision morally only if one is confident that those resources will serve at least as important a purpose as they would in sustaining one's life. That norm is not easy to fulfill, because without being very costly or labor intensive, ANH provides the great benefit of allowing one to live. Here again, one must assiduously avoid rationalizing. One must not direct that the resources that otherwise would be expended to provide ANH be used for other purposes because one would rather be dead than in PVS. Moreover, because the choice to forgo care is an act of freely given mercy, no one can make this decision for the patient. It is impossible to be merciful on behalf of another.

ABORTING NON-VIABLE FETUSES WHEN THE MOTHER'S LIFE IS NOT THREATENED

In a joint article entitled "Care for the Beginning of Life," Jean deBlois, C.S.J., and Kevin O'Rourke comment on the 1994 *Ethical and Religious Directives for Catholic Health Care Services* approved by the U.S. bishops. They claim that Directive 48 "succinctly defines the limits within which the moral assessment of treating extrauterine pregnancy must take place. The sole criterion proposed is that treatment must not constitute a direct abortion." However, Directive 47 limits accepting death as a side effect. A medical intervention that will result in the unborn child's death is licit only if there is "a proportionately serious pathological condition of a pregnant woman." xix

How does the principle of double effect bear on the case of a woman pregnant with an anencephalic child? An anencephalic infant lacks much

of its brain, skull, and cap due to the neural tube's failure to close during the embryo's early development. If brought to term, the child will not be able to achieve normal cognitive or affective development because it has no functioning cerebral cortex; in fact, it will die very soon, probably within hours of birth.*

In "Anencephaly and the Management of Pregnancy," deBlois claims that anencephaly can be diagnosed in the first trimester and argues that "once the diagnosis is made, there seems to be no purpose in maintaining the pregnancy." Since the pregnancy involves physical risks to the mother along with "the emotional trauma suffered by a couple upon diagnosis of anencephaly," deBlois concludes that "terminating the pregnancy" can be justified by the principle of double effect:

The intervention which terminates the pregnancy is taken to avoid the continued risk to the mother posed by carrying an anencephalic fetus. The risks cannot be avoided in any other way. The death of the fetus, while unintended, is unavoidable. It is a matter of prudential judgment that the good being sought in this case is of due proportion to the evil permitted. While the mother's life is not in imminent danger, there is the real possibility of maternal harm as pregnancy advances. Since the condition of the fetus deprives it of any potential for development, the proportion seems adequate to justify terminating the pregnancy. *xxii*

This analysis is riddled with problems. DeBlois's presupposition that prenatal diagnosis can be moral even when it is done with a view to discovering candidates for abortion is not justified and is at odds with explicit Catholic teaching. Her apparent assumption that it is possible to provide an absolutely certain diagnosis of anencephaly prior to birth ignores relevant medical findings. Her representations about the risks to the mother of carrying an anencephalic child are misleading.

Unfortunately, this article cannot treat all of those issues. But the assumption that the abortion would reduce the risk to the mother's health and remove her psychological trauma should not go unchallenged. DeBlois says nothing of the physical risks associated with abortion itself, such as the risk of cervical muscle damage and damage to the uterine wall, which can lead to scarring, future miscarriages, and ectopic pregnancies. And it is by no means clear that psychological trauma is

removed or even reduced when the unborn child is aborted. In exchange for a possible short-term release of tension, there is the daunting prospect of post-abortion syndrome, which has caused severe psychological trauma in many women who were advised to turn to abortion as a solution to their problem.

It is of inestimable value to both child and parents for the pregnancy to be brought to term, not least so that the parents can use what little time there is to bond with the child. A study of couples who learned that their pregnancy involved a lethal abnormality records the following poignant remark of one mother who gave birth to an anencephalic infant: "We saw him. If I had had a termination, we would have nothing to remember. And I would have wondered if the scans were wrong. I would have had that termination on my conscience for the rest of my life."xxv Besides drawing attention to the psychological benefit to the woman of bringing her child to term, this comment underscores the significance of the woman's spiritual welfare. As Mother Teresa of Calcutta puts it, abortion involves two deaths: the death of the unborn child and the death of the woman's conscience. To encourage a woman to prefer an illusory health advantage and a possible temporary respite from emotional trauma over the very life of her unborn child is to disregard not only the value of the child's life but the woman's spiritual welfare as well.

DeBlois's willingness to accept the physical and psychological risks of abortion undermines her claim that because it removes the physical and psychological risks of carrying an anencephalic child to term, the abortion would not be an intentional killing. It makes little sense to argue that one's intention is not the death of the child but the avoiding of risks when the child's dying entails greater risks. But even if one were to concede that the abortion would not be directly intended, it does not follow that it would be morally justifiable. Mother and child must be treated as persons with equal rights and dignity. When one bears that in mind and applies the Golden Rule, it becomes evident that it is grossly unfair to proceed with a treatment that will result in the death of one for any reason other than to save the life of the other. Even in such a conflict situation, which virtually never occurs in modern medical facilities, reasons must be given for choosing to save one rather than the other. But

there is no conceivable justification for removing a minor risk to the mother's health and attempting to reduce her psychological trauma when doing so requires the death of her unborn child.

Why do ethicists like deBlois argue that the (alleged) removal of physical danger and emotional trauma can justify consenting to a procedure that would result in the death of the anencephalic unborn child? Given the approval of such procedures in some ostensibly Catholic hospitals, her argument is perhaps an effort to justify what those hospitals already are doing to accommodate women pregnant with anencephalic children. In any case, her analysis manifests the same attitude toward the value of life that characterizes the effort, criticized above, to justify removing ANH from PVS patients. The assumption once again is that bodily life is not valuable in itself but only as the condition for one's participating in other goods. Life is regarded not as intrinsically but only as instrumentally good.

DeBlois claims that "anencephaly makes integrated development impossible" and notes that human development is significant only if it is integrated. She explains that "human life, while dependent upon a physiologic substrate, involves psychologic, social and creative capacities as well" and insists that "human life involves more than simply biologic life." While the latter statement is true, in context deBlois's assertion plainly implies that she does not consider the anencephalic fetus to be a human person.

If deBlois really holds that the anencephalic fetus is not a person, one wonders why she bothers to insist that in aborting it one need not directly intend its death. She could simply argue that one has sufficient reason to justify intentionally killing a non-person. Moreover, if deBlois holds that the anencephalic fetus is not a person, consistency would require her to hold that if it were brought to term and born alive, there would be no point in baptizing it. But deBlois provides no credible basis for holding that the anencephalic fetus is not a human person. That its neural tube fails to close later on in gestation is no reason to deny that, as with all of us, such a fetus becomes a person at fertilization, when integrated development begins. And while the affliction of anencephaly hinders normal development, the development these infants do achieve—

evident in their virtually perfect bodies-is by no means entirely unintegrated.

If, on the other hand, deBlois acknowledges that the anencephalic fetus is a person, then her observations about what constitutes significant human life provide no support at all for her claim that the abortion can be justified. She avoids dealing with these problems by failing to be explicit about the personal status of the anencephalic fetus.

The implication that it is possible for a human being not to be a person reveals an underlying dualistic anthropology that fails to recognize the inherent value of bodily life. On such a view, bodily life is not identified with the person and is considered valuable only if it enables one to participate in other goods.

CONCLUSION

A common assumption underlies the reasoning of many who hold the positions I have argued against. Those who justify PAS, those who support the withdrawal of ANH from PVS patients, and those who defend the abortion of anencephalic fetuses tend to suppose that bodily life is good only instrumentally and not in itself. Underlying that assumption is a dualistic anthropology, according to which the human person is not considered an integral unity of body and soul. Rather, the person's true self is thought to be somehow distinct from his body.

This dualistic perspective leads one to assume that when the body cannot sustain a person's satisfactory participation in human goods, he is better off dead. Those who hold this view often suppose that the body can be killed without compromising the person and that in death the soul is "freed" from the body. Such a perspective fails to recognize that death is a radical dissolution of an integrated unity rather than an event that in itself offers freedom. Christianity holds, to the contrary, that our full freedom comes only with the resurrection of the body, when death is overcome and the body is once again brought into personal unity with the soul.

The dangers of a dualistic anthropology extend far beyond the way it shapes attitudes on the specific questions we have considered. When society embraces the view that bodily life is valuable only when it enables a person to participate satisfactorily in a broad range of goods, then it is not only the lives of PVS patients and the anencephalic unborn that will be in peril. The lives of the severely disabled also will be considered expendable, as will many others, including newborns and even alert adults thought to have a very meager participation in goods other than life itself. Indeed, a proportionalist analysis will consider expendable all persons whose participation in human goods is judged not to offset the burden they pose to society. The inexorable and frightening logic of the view that human life is not intrinsically valuable should move us to respond convincingly to those who endorse that idea.

NOTES

i. John Paul II, *Evangelium Vitae* (Washington, D.C.: U.S. Catholic Conference, 1995), 65: *AAS* 87 (1995) 476, recalls that "Pius XII affirmed that it is licit to relieve pain by narcotics even when the result is decreased consciousness and a shortening of life, 'if no other means exist, and if, in the given circumstances, this does not prevent the carrying out of other religious and moral duties.' [Pius XII, Address to an International Group of Physicians (24 Feb. 1957) III: *AAS* 49 (1957) 147; *cf.* Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, III: *AAS* 72 (1980) 547-548.] In such a case, 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."

ii. Bryan Robinson, Mary Jane Stevenson, and Aldina Vazao Kennedy, "Kevorkian argues in opening statement that he did not intend to kill, says he did his duty as a doctor," *Court TV*, 22 March 1999, Online, Internet, available http://www.courttv.com/trials/kevorkian/032399_pm_ctv.html.

iii. See John Finnis, *Moral Absolutes: Tradition, Revision, and Truth* (Washington, D.C.: The Catholic Univ. of America Press, 1991); Germain Grisez, *The Way of the Lord Jesus*, Vol. 1, *Christian Moral Principles* (Chicago, Franciscan Herald Press, 1983), 141-71; John Paul II, Encyclical Letter *Veritatis Splendor*, 71-83: *AAS* 85 (1993).

iv. Vacco v. Quill, 80 F.3d 716, 727, 729 (2d Cir 1996).

v. Ibid.

vi. Ibid., 729.

vii. See David Orentlicher, "The Legalization of Physician-Assisted Suicide," *The New England Journal of Medicine*, 335/9 (29 August 1996) 663-67.

viii. Compassion in Dying v. State of Washington, 79 F3d 790 (9th Cir 1996).

- 9. "Ethical Issues in Health Care," Saint Louis University Health Sciences Center, Center for Health Care Ethics, 18/8 (April 1996) 2.
- x. A vegetative state tends to be regarded as "persistent" if it lasts any time from one to three months and "permanent" after a year or more.

xi.O'Rourke, "Ethical Issues," 2.

xii. Ibid.

xiii. Apparently, many physicians in the United States share this mistaken view. In Payne et al., "Physicians' Attitudes about the Care of Patients in the Persistent Vegetative State: A National Survey," Annals of Internal Medicine, 125/2 (15 July 1996) 104-10, researchers point to an emerging consensus of attitudes and beliefs among physicians who care for PVS patients. With respect to their attitudes, of the 319 doctors who responded, 89% consider it ethical to withhold ANH from PVS patients; 65% consider it ethical to transplant vital organs from PVS patients; and 20% consider it ethical to administer lethal injections to hasten the death of such patients. With respect to these physicians' beliefs about the condition of PVS patients, only 13% think such patients are aware and have the experience of hunger and thirst; and only 30% believe these patients feel pain. The report concludes: "When evaluating the appropriateness of treatments for patients in the PVS, neurologists and medical directors largely concur. Most physicians in both groups believe that patients in the PVS would be better off dead; that it is not necessary to provide aggressive therapeutic interventions; and that all therapeutic interventions, including artificial nutrition and hydration, can be withheld in certain circumstances. The areas of consensus are remarkable and suggest that an ethical standard that physicians believe should be followed when caring for these patients may be emerging" (104). Of particular interest is the revelation that almost half of the doctors who responded "agreed that patients in the PVS should be considered dead....Defining patients in the PVS as dead would eliminate the physicians' responsibilities to these patients and thus may, in some respects, appeal to some physicians" (108). If such patients were "defined as dead," all questions about care for PVS patients would be instantly resolved, and harvesting organs from them would not violate U.S. law that prohibits harvesting organs from living patients (108).

xiv. O'Rourke, "A Response to William E. May's "Tube Feeding and the 'Vegetative State," *Ethics and Medics*, 24/4 (April 1999) 3-4.

xv. "Tube Feeding and the 'Vegetative State," *Ethics and Medics*, 23/12 (December 1998) 2.

xvi. Andrews et al., "Misdiagnosis of the Vegetative State: Retrospective Study in a Rehabilitation Unit," British Medical Journal, 313 (6 July 1996) 13-16, report on a study of forty PVS patients at Britain's Royal Hospital for Neurodisability. The researchers found that seventeen (43%) had been misdiagnosed by their referring physicians as being in PVS; thirteen (33%) slowly emerged from the vegetative condition during rehabilitation therapy; and only ten (25%) remained in the vegetative state. This disturbingly high incidence of misdiagnosis occurred despite the fact that in most cases, the diagnosis was "made by a neurologist, a neurosurgeon, or rehabilitation specialist-all of whom could have been expected to have experience of the vegetative state" (15). The researchers point out that misdiagnosis can occur even when the patient is assessed regularly and the observations of family and caregivers are taken into account. The conclusions of this British study of PVS, which is among the largest and most comprehensive available, echo the findings of an earlier U.S study of PVS patients referred to the Healthcare Rehabilitation Center in Austin, Texas. Childs, et al, "Accuracy of Diagnosis of Persistent Vegetative State," *Neurology*, 43 (August 1993): 1465-67, report that "of the 49 patients referred in coma or PVS, 18 (37%) received a change in diagnosis at or shortly after admission" (1466).

xvii. One might ask what a financially strapped family is to do when it cannot afford a hospital room and basic nursing care. It seems to me that the members of such a family can make arrangements for the loved one in PVS to stay at home, with feeding tube intact. Their responsibility simply would be to do what they can to provide for the patient's basic needs without ignoring their other responsibilities. Since what they can do under such circumstances is likely to be quite a bit less than what a nursing staff could do in a hospital room, the situation can be distressing. Proceeding in this way may not be as neat and easy as removing a feeding tube, but neither does it involve the choice to kill or wrongly cut off care. Rather, it maintains solidarity with the patient.

xviii. "Care for the Beginning of Life: The Revised *Ethical and Religious Directives* Discuss Abortion, Contraception, and Assisted Reproduction," *Health Progress* (Sept.-Oct. 1995) 39.

xix. National Conference of Catholic Bishops, *Ethical and Religious Directives* for Catholic Health Care Services (Washington, D.C.: U.S. Catholic Conference, 1995), directive 47.

xx. Still, the extent of the pathology varies, and some anencephalic babies live a month or more. See D. Alan Shewmon, "Anencephaly: Selected Medical Aspects," *Hastings Center Report*, 18/5 (Oct.-Nov. 1988) 11-15.

xxi. "Anencephaly and the Management of Pregnancy," *Health Care Ethics USA* (fall 1993): 2.

xxii. Ibid., 3.

xxiii. See Congregation for the Doctrine of the Faith, *Instruction on Respect for Human Life in its Origin and on the Dignity of Procreation* (1987) 1,2: AAS 80 (1988); Catechism of the Catholic Church, no. 2274.

xxiv. Stumpf *et al.*, "The Infant with Anencephaly," *The New England Journal of Medicine*, 322/10 (8 March 1990): 670, report that "it may not be possible in all cases to distinguish anencephaly from other very severe anomalies of the head...For purposes of genetic and reproductive counseling and epidemiologic reporting, the diagnosis should be confirmed by an experienced observer following delivery of an abortus or stillborn infant." Even after birth, "errors in diagnosis have been described in the literature, by surveillance programs, and by our task force in a survey of pediatric training programs." Also see Shewmon, 11-15.

xxv. Chitty *et al.*, "Continuing with Pregnancy after a Diagnosis of Lethal Abnormality: Experience of Five Couples and Recommendation for Management," *British Medical Journal*, 313 (24 August 1996) 479-80.

xxvi. DeBlois, "Anencephaly," 3.

xxvii. Ibid., 2.