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Case Study:

Paul Brophy, a 48-year old fireman living in Boston, married to Patricia Brophy for 27 years, suffered a subarachnoid hemorrhage as a result of a ruptured basilar tip aneurysm on March 22, 1983. In order to correct the aneurysm, Brophy underwent major surgery involving a right frontotemporal craniotomy and a clipping of the basilar tip aneurysm. Postoperatively, he never regained consciousness, and has remained in a persistent vegetative state. Subsequent to his surgery of April 6, 1983 and prior to his discharge on June 28, 1983, Brophy received multiple CT scans, which showed a complete infarction (destruction of tissue secondary to lack of blood flow) of his left posterior cerebral artery and infarction of the right temporal lobe of the brain. In January, 1985, Patricia Brophy, with the consent of the five Brophy children, all of whom are adults, petitioned to have all life sustaining treatment removed from her husband, including the discontinuation of all artificial nutrition and hydration.

What decision should the court make?

Divergent Opinions

In March, 1986, Judge Kopelman of the Family Court, Norfolk Division, State of Massachusetts, after agreeing that "it is highly unlikely that Brophy will ever again regain cognitive ability to purposefully interact with his environment" and after stating that "if he (Brophy) were presently competent he would choose to forego the provision of food and water," determined that the artificial feeding and hydration must be continued because

> it is ethically inappropriate to cause the preventable death of Brophy by the deliberate denial of food and water, which can be provided to him in a noninvasive, nonintrusive manner which causes him no pain and suffering, irrespective of the substituted judgment of the patient.[1]

In September, 1986, the decision of Judge Kopelman was reversed, and the Supreme Court of the Commonwealth of Massachusetts allowed the removal of the gastrostomy tube, stating

> 1) The State's interest in preservation of life includes the recognition that life is more than mere corporeal existence. The patient's humanity itself may be degraded by the processes designed to sustain existence. It is for the individual,

not the State, to decide the value of continued existence. That value may include an interest in maintaining bodily integrity and avoiding invasive and demeaning medical treatment.

2) The State's interest in prevention of suicide is not implicated in Brophy's case. The affliction rendering Brophy incapable of swallowing, not the removal of the gastrostomy tube, will be responsible for his death.

3) Refusing medical intervention merely allows the disease to take its natural course; if death were eventually to occur, it would be the result, primarily, of the underlying disease, and not the result of a self-inflicted injury.[2]

The legal opinions expressed in court decisions do not determine ethical issues. Rather, legal decisions should be based upon ethical norms. But sometimes differing court decisions may be used to indicate a lack of ethical consensus concerning specific medical procedures. The diametrically opposed legal opinions in the Brophy case demonstrate the lack of ethical agreement in regard to use of artificial hydration and nutrition for patients in irreversible coma.[3]

The lack of ethical agreement in regard to treatment of patients in irreversible coma is also evidenced in statements from different professional organizations. For example, the American Medical Association (AMA) has declared:

> Even if death is not imminent but a patient's coma is beyond doubt irreversible and there are adequate safeguards to confirm the accuracy of the diagnosis and with the concurrence of those who have responsibility for the care of the patient, it is not unethical to discontinue all means of life prolonging medical treatment. Life prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration.[4]

On the other hand, a working group of the Pontifical Academy of Science, consultors to Pope John Paul II, after making a distinction between treatment (medical interventions) and care (ordinary help due to bedridden patients), said:

> If the patient is in permanent coma, irreversible as far as it is possible to predict, treatment is not required but care including feeding must be provided.[5]

While this article will not solve all questions in regard to the ethical and medical use of artificial hydration and nutrition, we wish to offer a few distinctions from the Catholic ethical tradition which may help to dispel some of the disagreement concerning the use artificial hydration and nutrition when a person is in an irreversible coma or persistent vegetative state.

Imminent Death

One confusing factor in determining ethical health care for seriously ill patients is phrases such as "imminent death" and "terminal condition". These phrases are often invoked as though they determine a patient's medical care. For example, in the cases of Karen Quinlan and Paul

Brophy, the lower courts, which refused permission to remove life support mechanisms, considered imminence of death an important issue. The courts and many physicians often use the terms "imminent death" and "terminal condition," to imply that a physician can predict that a patient will die of a fatal pathology within a few days or weeks *in spite of the fact that life prolonging methods are already being utilized.* Using these terms in this sense as significant factors in making ethical and legal decisions for seriously ill persons begs the question. The important issue is not how long the patient might live *with* life support systems, but *whether* a life support system should be initiated in the first place, or once intitiated, for what reasons it may be withdrawn.

Aside from murder and suicide, death occurs from a pathology internal to the physiological system which so unbalances homeostasis that the patient cannot survive. Life-prolonging therapy seeks to remove a potentially fatal pathology, or it aims at circumventing or delaying the effect of the fatal pathology. Thus, a person undergoes surgery to remove cancer or a person agrees to kidney dialysis in order to circumvent renal failure. A person in an irreversible coma or in a persistent vegetative state, cannot chew and swallow. Proximately, this is due to malfunction of the swallowing mechanism; remotely, it is usually due to a dysfunction in the cerebral cortex. Thus a person in an irreversible coma or persistent vegetative state will die of a fatal pathology—the inability to swallow—in a short time, unless life-prolonging devices are utilized to circumvent the pathology

Withholding artificial hydration and nutrition from a patient in this debilitated condition does not induce a new fatal pathology. Rather, it allows an already existing fatal pathology to take its natural course. In like manner, when a respirator is removed, the person usually dies because of malfunction in the cardiopulmonary system, which pathology had been circumvented by use of the respirator. From the ethical perspective, the intention of the persons removing the life support system is not to kill the patient, but rather to discontinue therapy which is not beneficial to the patient, or to remove a burden from the patient. The ensuing death is foreseen but not directly intended and the death is ethically allowable because of the condition of the patient. This distinction between inducing a fatal pathology and allowing a fatal pathology to take its natural course because circumventing it will not benefit the patient, is aptly expressed by the Supreme Court of Massachusetts in the Brophy case.

Hence, when making ethical or legal decisions concerning the care of persons in irreversible coma or with other serious pathological conditions, rather than discussing whether death is imminent, or whether the patient is terminally ill, we should ask whether a fatal pathology is present. If a fatal pathology is present, the significant ethical question is not whether death is imminent, *but rather whether there is a moral obligation to seek to remove fatal pathology or at least to circumvent its effects.* Hence, when determining for oneself or for another whether to utilize life-prolonging therapy, the

most fundamental question becomes, "Is there an ethical obligation to seek to remove or circumvent the fatal pathology?" If not, the pathology may be allowed to take its normal course.

Basis for Ethical Obligation

How decide to treat a fatal pathology or let it take its natural course? One of the basic ethical assumptions upon which medicine and efforts to nurse and feed people are based is that life should be prolonged because living enables us to pursue the purpose of life. Thus, there is a strong assumption that there is an ethical obligation to prolong life. But does that obligation ever cease? Clearly, it would cease if prolonging life does not contribute to striving for the purpose of life. Hence, if efforts to prolong life are ineffective or useless insofar as pursuing the purpose of life is concerned, or if prolonging life results in a severe burden for the patient insofar as pursuing the purpose of life is concerned, then the ethical obligation to prolong life is no longer present.

What is the "purpose of life?" People use many expressions to define this purpose, for example, "to be happy", "to love God and neighbor", "to relate to others". The Catholic view of the purpose of life in regard to decisions of health care was stated by Pope Pius XII in 1957. This statement is still accepted as accurate and complete for determining the ethical treatment of seriously ill patients. The Pope explained:

> Normally one is held to use only ordinary means, according to circumstances of persons, places, times and culture, that is to say, means that do not involve any grave burden for oneself or another. A more strict obligation would be too burdensome for most people and would render the attainment of the higher, more important good too difficult. **Life, health, all temporal activities are in fact subordinated to spiritual ends.**[6]

Thus, in traditional Catholic teaching, when making decisions in medical ethics about care for people with fatal pathologies, the spiritual goal of life is emphasized. In order to differentiate those means to health and life which are ethically mandatory from those which are optional, Catholic teaching uses the terms "ordinary means" and "extraordinary means". "Ordinary means" to foster health or to prolong life, are those means which are mandatory because they offer hope of benefit to the patient and may be utilized without grave burden to the patient. "Extraordinary means" to foster health and prolong life are on the other hand, those means which are optional either because they are ineffective insofar as benefit to the patient is concerned, or because they involve a grave burden.[7] But the foregoing definitions are incomplete unless we explain the terms "benefit to the patient" and "grave burden to the patient" in relation to the purpose of life. Thus, a more adequate and complete explanation of "ordinary means" to prolong life is: Those means which are beneficial because they enable a person to strive for the spiritual purpose of life. A more adequate and complete explanation of "extraordinary means" to prolong life is: Those means that are optional because they do not enable a person to strive for the spiritual purpose of life or because they involve a grave burden insofar

as striving for the purpose of life is concerned. While it may seem redundant, it is important to insist that one cannot judge what is beneficial for a person, or what is a grave burden in regard to the spiritual purpose of life unless one knows the condition of the individual patient—not only the physiological condition, but the social and spiritual condition as well. Thus, Pope Pius XII stated that, when decisions are made concerning medical care, "circumstances of person, places, times and culture must be considered."

The terms "ordinary and extraordinary means" have become commonplace outside the Catholic community in legal, medical and ethical statements regarding the obligation to utilize specific life-prolonging medical therapy. But too often, when using the terms "ordinary or extraordinary means" to prolong life, ethicists, judges or physicians fail to stipulate that the criteria to evaluate life-prolonging medical therapy is the spiritual purpose of life, not the preservation of mere physiological function. Moreover, they often use the terms ordinary and extraordinary means as abstract, and *a priori* designations with no reference to circumstances of persons, places, times and culture. Thus, to state "artificial nutrition is an ordinary means to prolong life," without reference to the patient's medical condition, is meaningless. Or to state that "ordinary means of preserving life are means which can effectively preserve life, without imposing grave burden on the patient" is an incomplete statement.[8] What does it mean "to effectively preserve life"? If the mere physiological function of a person is preserved, as is the case of those in irreversible coma, does that enable the person to strive for the spiritual ends of life? As we shall see, mere physiological function does not enable a person to strive for the spiritual purpose of life. Hence, it seems that some of the confusion attributed to the terms "ordinary and extraordinary means" to prolong life, arises because people are not specific enough about the circumstances and goal of life, and hence not specific enough about the goal of medical care. [9]

Ineffective Therapy

In order to pursue the spiritual purpose of life, one needs a minimal degree of cognitive-affective function. Hence, if medical efforts to restore cognitive-affective function in an adult can be judged ineffective or if it can be judged that an infant will never develop cognitive-affective function, and if a fatal pathology is present, then the adult or infant may be allowed to die. There is no need to seek to remove the fatal pathology or circumvent its effects if the efforts would not enable the individual to achieve cognitive-affective function and thus strive for the spiritual purpose of life. This is the precise Catholic ethical justification for discontinuing artificial hydration and nutrition for people in irreversible coma, not the fact "that benefits or treatment outweigh its burdens," as the AMA statement indicates.[10] Physiological function which can be prolonged long after cognitive-affective function ceases irreparably, is not a sufficient reason

for prolonging life. Physiological function without the potential for cognitive-affective function does not benefit the patient and does not contribute to pursuing the purpose of life. The primary role of physiological function is to support cognitive-affective function, but we know physiological activity can continue long after cognitive-affective function is irreparably lost because of brain damage. Some physicians and ethicians maintain that the diagnosis of irreversible coma or persistent vegetative state are never "absolutely certain". They cite cases of people who have recovered consciousness after an "irreversible coma", and imply that it is never safe to make a medical judgement that therapy is ineffective for a person in a persistent vegetative state or an irreversible coma.

Remembering that all valid medical decisions are based on physiological evidence, it is well to recall that a diagnosis of irreversible coma or persistent vegetative state utilizes diagnostic studies of brain damage as well as observed lack of cognitive-affective and physiological function over a prolonged period of time.[11] While this careful diagnosis will not rule out with absolute certainty the possibility for "recovery," it does afford sufficient evidence for safe medical diagnosis and prognosis. Only two cases in medical literature report patients who regained cognitive awareness after a verified diagnosis of irreversible coma.[12] This posits an accurate diagnosis in about 99.98% of the cases. Medical decisions do not admit of greater certitude given that medicine is an art as well as a science. If physicians waited until absolute certitude could be achieved, they would never act. Moreover, we must bear in mind that "recovery" from an irreversible coma does not imply that the person recovers full cognitive-affective function or physical mobility. In fact, the state of the persons who "recovered" from irreversible coma was severely impaired—so impaired that the condition of the person might be considered a grave burden insofar as striving for the spiritual purpose of life is concerned.[13]

Still a Human Being

Is the person who has physiological function but no hope of recovering cognitive-affective function still a human being? Yes, but there is no ethical obligation to strive to prolong the life of that human being. There is an ethical obligation to keep the person comfortable and we will have another word to say about comfort care. (See section to come herein.) But the usual ethical obligation to seek to prolong the life of another person, when a fatal pathology is present, ceases, once it can be determined that the person will not recover, or does not have the potential for developing cognitive-affective function. Notice that the physical pain, or lack of it, associated with the life-prolonging therapy, is not in itself the sole determining factor when making an ethical decision whether therapy is effective or ineffective in regard to restoring cognitive-affective function. For this reason, Justice Kopelman's decision in the circuit court in the Brophy case was flawed, because life-prolonging therapy may be withdrawn as soon as it is obvious that it is ineffective insofar as restoring cognitive-affective function is

concerned, as the Supreme Court of Massachusetts indicated when it reversed Justice Kopelman's decision. The degree of physical pain may influence the ethical judgment concerning the burden that prolonging life entails, but not the judgment concerning the effectiveness or ineffectiveness of life-prolonging therapy.

A Grave Burden

Whether prolonging life will result in a grave burden for the patient, insofar as striving for the spiritual purpose of life is concerned, is a more difficult ethical judgment. But simply because it is difficult does not mean it is to be avoided or supplanted by a law which eliminates consideration of some meaningful circumstances. If the person with a fatal pathology is competent, then he or she should be allowed to make the decision whether or not prolonging life would be a grave burden in regard to pursuing the purpose of life. The seriously ill person is not "autonomous" in the absolute sense, as some ethicists would indicate. Hence, the decision about prolonging life should take personal, familial, and social circumstances into account, because one has responsibility to self, family and society insofar as fulfilling the spiritual purpose of life is concerned. For example, a father whose life is threatened because of cancer, may decide that his purpose in life would be better fulfilled if he rejected chemotherapy, surgery, or hospitalization in order to devote his time to his family during his remaining days, and to devote his savings toward the education of his children. Given the circumstances, the father is not "choosing death." Rather, realizing that he must die sometime, he chooses to provide for his family as well as he can, rather than choosing to prolong his life for two, three, or even 10 years and, as a result, endangering other values, such as meaningful time with loved ones or the education of his children. Choosing in this manner is not suicide; the father foresees that death may occur sooner than if he entered a program of therapy, but his direct intention is to benefit his family. His earlier death would be a necessary, but undesired, side effect on his choice.

When making the ethical decision about grave burden, one seeks to assess the spiritual burden that would result if life is prolonged, not simply the physical burden which utilizing the life-prolonging therapy would entail. This distinction seems to be misunderstood by many ethicists, physicians and judges. Hence, when faced with the decision of whether or not to prolong the life of another person some consider the amount of physical pain as the only significant factor; the psychic pain and anguish associated with living in a severely debilitated condition are often overlooked. But whatever the source of pain, it is the relationship of the pain to pursuing the purpose of life that matters. This judgment may differ from person to person. Thus, severe pain or great expense, causing the loss of other more important values, may result in a decision by one person that he would have a very difficult time striving for the purpose of life. On the other hand, another person, faced with the same pain or expense, may

determine that for him, a grave burden would not result insofar as striving for the purpose of life is concerned. Recall that decisions in regard to prolonging life are to be made "in accord with circumstances of person, places, times and culture." Thus, a person with a fatal pathology has many other factors besides his or her physiological condition to consider before making a decision about fitting therapy.

Proxy Decisions

Even more difficult ethical decisions are involved when a decision based upon grave burden must be made for another person who is incompetent of deprived mental abilities. If the person for whom the proxy decision must be expressed, when still competent, stated how he or she wished to be treated after losing competency, then those wishes should be followed out of respect for the person. But sometimes proxy decisions must be made with no information about the presumed desires of the incompetent person. In these cases, decisions are made by asking "What would any reasonable person desire, given the circumstances?" For example, if the life of an infant with a fatal pathology could be prolonged with some hope that the infant would develop cognitive-affective function, but if prolonging life would involve great pain, or expense, or inhuman living conditions, would a reasonable person attempt to remove the pathology or arrest its effects? Ethically speaking, if a fatal pathology is present, need a family consent to life-prolonging therapy for an infant who has severe genetic disease such as Lesch-Nyhan Syndrome or who will require nursing care 24 hours a day for the rest of his or her life? Should all children born with severe complicated immunological deficiency (SCID) be raised in plastic bubbles, as was Baby David in Houston? In the case of Baby David, the means to prolong life were not painful but after a time, the life of Baby David became severely burdensome and, at age 13, he requested to have the bubble removed. Again, the proxy is called upon to assess the burden resulting from prolonged life, not the physical burden intrinsic to the means to prolong life. Even though the means to prolong life may be judged inexpensive or painless, using them may subject another human being to a life that is severely burdensome.

When making decisions for others, the proxy must realize that a person with painful and impaired physiological function, even if his/her cognitive-affective function is weak, can still pursue the spiritual purpose of life. Thus, simply because an infant or an incompetent adult is debilitated or retarded does not imply automatically that he or she can be allowed to die from an existing fatal pathology. Moreover, a fatal pathology should never be induced in debilitated infants. But on the other hand, the notion that there is an ethical obligation to prolong the life of every infant or incompetent adult with a fatal pathology, simply because prolonging life is possible, is not ethically justifiable. Prolonging life may result in a grave burden for the infant or adult, insofar as pursuing the purpose of life is concerned. Hence, when determining whether to seek to

remove or circumvent a fatal pathology in a newborn infant or for an adult who is not competent, personal, familial and social factors must be taken into account, as they are when one makes a decision for oneself.

Comfort Care Distinction in Papal Document

Maintaining that the life of a person need not be prolonged when a fatal pathology is present does not imply that the person should be neglected. Every dying person should be given spiritual and physical care. The ethical obligation to keep dying patients comfortable leads some to demand artificial hydration and nutrition for all patients, even those who are in irreversible coma.[14] But is there any medical indication that persons in this condition feel physical pain? The neurological experts consulted in the Brophy case did not think so. In hospices and infirmaries of religious sisters, (the latter institutions being the embodiment of compassionate care for the dying), artificial hydration and nutrition are seldom utilized once a dying patient lapses into a coma. In sum, evidence seems to be lacking that removing or withholding tube feeding from individuals in deep coma or persistent vegetative state results in great pain for the patient.

Conclusion

The Brophy case and the decisions of the courts in Massachusetts illustrate the divergence of ethical opinion in regard to tube feeding and hydration. However, though there is disparity and disagreement, it seems that some agreement may be reached in this matter if the distinctions of Catholic tradition are utilized. The significant ethical question in preserving our own life or the life of another person is: "Is there an ethical obligation to prolong life?", not, "are we able to prolong life?" Moreover, all decisions about prolonging life should be made in view of the spiritual purpose of life and in view of the significant circumstances. Mere physiological function does not achieve the purpose of human life. While inducing the pathology that causes death in an innocent person is never ethical, allowing a fatal pathology to take its normal course, not seeking to remove it nor circumvent its effects, in some circumstances is an ethically acceptable choice.

References

1. Commonwealth of Massachusetts, The Probate and Family Court Dept., Norfolk Division, Patricia E. Brophy, guardian of Paul E. Brophy, *Plaintiff vs. New England Sinai Hospital, Inc., Defendant*, (Oct. 21, 1985), n. 25.

2. Supreme Court of Massachusetts, *Patricia E. Brophy vs. New England Sinai Hospital, Inc., Norfolk*, (Sept. 11, 1986), pp. 21-28.

3. "Irreversible coma" signifies a state of unarousable unresponsiveness, the absence of any psychologically understandable response to external stimulus or inner need from which it can be judged from medical signs that the patient will not recover. "Persistent vegetative state" describes the condition of patients who survive for prolonged periods of

time in a comatose condition. Patients in this condition may be "awake" even though their behavior does not demonstrate any evidence of conscious intelligence. Plum and Posner, *Diagnosis of Stupor and Coma,* (Philadelphia, F.A. Davis, Co., 1972), pp. 5, 6, 233-236. For a more complete definition of the persistent vegetative state cf. Brophy, "Decision of Massachusetts Supreme Court," p. 4, footnote 4. Also President's Commission on Ethics in Medicine and Research, *Deciding to Forego Life-Sustaining Treatment,* 1983, pp. 174-75.

4. American Medical Association Council on Ethics and Judicial Affairs, (March 15, 1986).

5. "Artificial Prolongation of Life and Exact Determination of the Moment of Death," Pontifical Academy of Sciences, *National Catholic News,* (Oct. 30, 1985).

6. "The Prolongation of Life," *The Pope Speaks,* Nov. 24, 1957, Vol. 4 (1958), pp. 393-398.

7. This traditional definition is contained in several books on medical ethics, cf. Gerald Kelly, S.J., *Medical Moral Problems,* (St. Louis, Catholic Hospital Association, 1957), p. 134. C. McFadden, O.S.A. *Medical Ethics,* (Philadelphia, F.A. Davis, Co., 1964), p. 230.

8. "Statement on Uniform Rights of the Terminally Ill Act," NCCB Committee for Pro-Life Activities, (June 26, 1986).

9. A recent statement of the Congregation for the Doctrine of the Faith, *On Euthanasia,* (June 26, 1986) indicated that the terms "ordinary and extraordinary" are no longer useful. We would maintain they are still useful if properly understood. Moreover, the substitute terms recommended in the document, "proportionate" and "disproportionate" dispose for consequentialism or proportionalism, questionable moral methods.

10. AMA Council on Ethics and Judicial Affairs, *op. cit.*

11. See Reference 3.

12. Cranford, Roland, M.D., quoted in Decision of Massachusetts Supreme Court in Brophy Case, p. 10. Cf. also Levey et al, "Prognosis in Non-traumatic Coma" *Annals of Internal Medicine,* vol. 14, n. 3 (March, 1981), pp. 293-301.

13. *Ibid.*

14. Thus the document of the Pontifical Academy of Science states: "If the patient is in permanent coma, irreversible as far as it is possible to predict, (medical) treatment is not required, but care, including feeding, must be provided." The distinction between medical treatment and care is new in a papal document. Is it a meaningful distinction? Though the name may be different, the effect of artificial feeding is the same. It prolongs life for the comatose person. On the face of it, the statement of the Academy is paternalistic because it does not consider a person's wishes concerning treatment which may have been expressed before the person lapses into coma. Moreover, "circumstances of persons, places, times and cultures" are not considered in the statement. Thus, if one followed the document, one would be required to provide artificial feeding to a patient in permanent coma whether in an acute care hospital in the United States or dying at home in the Australian outback. In sum, the statement of the Pontifical Academy does not help solve the problems it addresses.