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Non-Heart-Beating Organ Donation: A Reply to Campbell and Weber

ABSTRACT. In the preceding commentary, Campbell and Weber raise two valid and important issues concerning non-heart-beating organ donation (NHBOD). First, because the procedure links withdrawal of life support and the potential for subsequent organ donation, the desire for organs may create a situation in which care of the dying individual has relatively less importance and the dying may receive suboptimal care. Second, even if concerns about care of the dying were dealt with adequately, there will not be enough non-heart-beating donors to significantly decrease the organ shortage that exists, making the procedure not worth the risk. We agree that attention to the important details of caring for the dying are, and must be, the primary concern of all health care workers caring for those individuals. Ensuring the patients' comfort, dignity, and autonomy, and providing for family and social support are the mainstays of this care. All policies for NHBOD should clearly support and mandate these concepts. Regarding the second concern, we agree that NHBOD is currently rare; however, evidence is increasing that this type of donation has great potential. Continued growth of the practice in this country will depend largely on public acceptance, which we believe will be directly influenced by whether the public perceives that care of the dying is not compromised by this procedure.

THE PRECEDING COMMENTARY by Margaret Campbell and Leonard Weber (1995) raises two major concerns regarding our case report of non-heart-beating organ donation (NHBOD) (DeVita et al. 1993) and concludes that, unless those concerns are addressed, they cannot endorse the practice. We will discuss each of the issues they raise and suggest a reconsideration of their conclusion.

Campbell and Weber argue that: (1) NHBOD will "compromise the developing standards" of care during the withdrawal of support from patients who have refused further life-prolonging therapy, and (2) the

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number of organs procured using this strategy (NHBOD) will be inconsequential and, therefore, NHBOD represents an unwarranted risk to individuals without likelihood of significant societal benefit.

COMPROMISING DEVELOPING STANDARDS OF CARE

We agree that no consensus has evolved regarding specific procedures for the withdrawal of life support. Campbell and Weber offer three *standards of care:* unrestricted visiting, adequate analgesia, and control of environment, all designed to improve patient comfort. In contrast, we believe that there is a broad consensus regarding certain *principles* (as opposed to standards of care) "governing" treatment withdrawal. It is generally agreed that (1) ensuring informed decision making, (2) supporting patient autonomy, (3) minimizing or eliminating discomfort (using the standards Campbell and Weber suggest), (4) maximizing human dignity (including support of the family and loved ones), and (5) maintaining accountability are important components of this process.

Campbell and Weber are concerned that the University of Pittsburgh Medical Center's (UPMC) NHBOD protocol (UPMC 1992) as outlined in the case report by DeVita et al. (1993) violates the above principles, or at least raises the possibility that they might be abrogated. The authors raise four specific concerns.

First, they maintain that restoring a "comfort-measures-only" patient to "full-code status" prior to the procurement of organs causes the patient to be treated contrary to a standard comfort-care protocol and allows therapy that may potentially harm the patient to occur. Two points must be made here. First, we believe that there is no *standard* comfort care; rather that which constitutes appropriate care is determined by (or for) each patient with as much guidance as possible from the patient or the surrogate. If a specific protocol were utilized, it is likely that some patients would receive care they do not wish and others would not receive care that they do wish. In our experience, the details of life-support withdrawal depend on many factors. For example, the timing of the withdrawal is commonly altered to some degree to accommodate the needs of the family. At times, the withdrawal may be delayed for as much as a day to allow family members to arrive from out of town. We recognize that in virtually all cases some compromises must be made between the "ideal" withdrawal protocol and the unique circumstances of each patient and family. Therefore, we believe that any specific protocol must be sufficiently flexible to accommodate patient and

family needs. We prefer to emphasize process and accountability rather than specific standards. At UPMC, the withdrawal procedure for both "ordinary" patients and potential organ donors follows the same principles, but neither is standard per se.

Second, we believe that if the patient (or surrogate) understands and consents to a full-code status, which improves the likelihood that the patient will be able to donate organs (something the patient desires), then de facto we are following the patient's wishes. Thus, we believe that our protocol is not contrary to the patient's wishes, but rather supports them. A more difficult issue is that chest compressions conceivably do harm to the patient. The use of relatively traumatic donation-oriented therapies, such as chest compressions and electrical defibrillation, must be approached very cautiously. On the other hand, ordering no cardiac resuscitation creates a situation in which a person who, by personal decision (or that of her surrogates) is a potential donor, may not be able to donate if she suffers asystole at a time or place where procurement is impossible. Therefore, our policy allows for full cardiopulmonary resuscitation (CPR), but only if the family or patient (if possible) agrees to it after being informed of this possibility, its rationale, and its potential effects. If they refuse CPR, it is with the understanding that should a cardiac arrest occur, CPR will not be done, and organ donation may not be feasible. We believe that this approach allows for informed consent, does not require patients to undergo therapy they do not want, and still allows patients the opportunity to donate their organs. We must add (as noted in our original paper) that organ donation is a secondary goal. We agree with Campbell and Weber that the primary goal must always be appropriate care of the dying patient.

In addition, there are other major interventions that would not be instituted if the patient were not going to be a donor. If a patient wishes to become an organ donor, it is a necessary condition that certain interventions occur in order for this wish to be carried out. A simple example is heparin therapy. We believe that it is reasonable to ask the patient or family for consent to use a drug of this sort, after informing them that not utilizing the drug greatly reduces the likelihood that organ donation will be possible, and that it is permissible to use it if consent is obtained.

Campbell and Weber's second point regarding comfort care involves the use of sedation and analgesia during the withdrawal of life support. There is certainly no national consensus regarding the indications for appropriate use of such therapy. Many physicians use these medications

to relieve suffering, and use physical signs compatible with distress as an indicator that there is pain that must be treated. Others withhold all medications from comatose patients based on the rationale that even if distress is occurring, the patient does not have sufficient cognition to interpret these sensations as noxious. Finally, some physicians believe that all pain must be avoided, rather than merely treated after the fact, and that using distress as an indicator requires that some patients will feel some pain in order to receive medication. These physicians argue that since comfort is a goal for such patients, allowing any pain is in a sense a failure. These physicians will prophylactically premedicate and dispense therapy to prevent discomfort. Campbell and Weber subscribe to the first approach, as do most physicians at UPMC.

Our emphasis is on the attempt to ensure good decision making, through informed consent and strict accountability, both internally and externally, and to assure that the drugs are utilized for comfort and not to intentionally hasten death. We disagree with the view that potentially beneficial comfort therapy necessarily should be withheld unless there is specific evidence that the patient has discomfort. The UPMC protocol takes the approach that discomfort should be avoided, but that the use of sedation must be linked to a specific rationale (preferably evidence of any distress). However, the physician may prescribe sedation because he or she believes that distress is occurring or may occur, even in the absence of signs of distress, although we would not, for example, endorse giving morphine for respiratory distress if the patient's respiratory rate is low and the accessory muscles are not being utilized.

Third, Campbell and Weber argue that the UPMC protocol does not pay enough attention to nonpharmacologic comfort interventions. The importance of privacy, warmth, quiet, and social support has been emphasized previously by Fox (1993). We agree with these concerns, and the protocol makes strong efforts to ensure that these concerns are addressed. The patient's primary nurse from the ICU stays with the patient, ensuring continuity of nursing care; fresh bed linens are provided if needed; and the patient remains in his or her own bed. There are one-to-one relationships for both the physician and the nurse with the patient and the family.

The obvious major difference in care between patients, such as the one in our case report, and other patients receiving comfort measures only in the ICU is not allowing the family to be at the bedside at the time of death, an important point for some families. The UPMC protocol origi-

nally did not allow the family to be present because of the "stress" on the family and the health professionals. In fact, in the case reported (as in many ICU situations), the family did not want to remain with the patient, and they said "good-bye" in the ICU. In a subsequent case, however, a family did want to stay with the patient. After careful discussion, we moved the patient to a quiet area near the OR and allowed the family to remain at the bedside until after death was pronounced. The patient was then brought to the waiting OR. Because of this favorable experience, the protocol has been revised to allow for this procedure if the family so desires. Researchers at UPMC are currently studying the perceptions and attitudes of health care workers and family members involved in the NHBOD process. By doing so, they hope to gain further insight into the effects of NHBOD on the participants.

Campbell and Weber's fourth point regarding comfort strategies is that the families of patients being considered for NHBOD may not be adequately supported because of the focus on organ donation rather than on the withdrawal of support and the dying process. We agree with this concern and believe that it is important to stress these needs in a protocol. For example, the UPMC policy requires that the family (and patient if possible) meet with an ethics consultant, the patient's primary nurse, and the ICU physician. In addition, a social worker is contacted, and pastoral care is offered to all family members. We begin the withdrawal procedure only when the family (who have agreed to the donation) are ready to begin. Finally, as noted, we now permit the family unlimited visitation in a comfortable environment (if they wish). We agree with Campbell and Weber that all policies for NHBOD should include this emphasis on social issues as well.

RELEVANCE OF NON-HEART-BEATING CADAVERS AS AN ORGAN SOURCE

The second major criticism Campbell and Weber offer is that even if there were no ethical concerns, NHBOD will not significantly increase the number of organs for transplantation. We disagree on two counts. First, other countries—notably Japan and Holland—have demonstrated that NHBOD can be a major, or even the sole, source of donor organs (see Kootstra and Daemen, forthcoming 1995). In Japan, where "brain death" is not recognized, non-heart-beating cadavers are the sole source of cadaveric organs, and in Holland, one-third of cadaveric organs come from NHBOD. Second, in the United States, there is evidence of the

potential for NHBOD to significantly increase the supply of organs, the findings of Campbell and Carlson (1992) not withstanding. UPMC has had two NHBODs per year from this protocol, a small number to be sure, but it constitutes 10 percent of the total annual procurements. Extrapolating that 10 percent to the national experience indicates an increase of 500 donors per year, with a potential yield of 1000 kidneys and 500 livers and pancreases.

Finally, NHBOD appears to be on a growth curve. Since UPMC passed the country's first NHBOD policy in 1992, the number of organ procurement organizations (OPOs) participating has increased from 3 to 25 (a 700 percent increase). Our research identified 20 NHBODs in 1992 and 45 in 1993, with 13 of 65 OPOs obtaining organs from NHBOD (DeVita, forthcoming 1995). Nineteen-hundred-ninety-four data from the United Network for Organ Sharing (UNOS) show that 20 of 66 OPOs (30 percent) have policies, and another 10 are developing them; 25 OPOs have procured organs from non-heart-beating cadavers (UNOS 1994). While these data are clearly inexact, they at least suggest that this source has the potential to become important. Continued growth of NHBOD in this country will depend largely on public acceptance, which we believe will be directly influenced by whether the public perceives that care of the dying is not compromised by this procedure. Only time will tell.

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