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Severe Neurological Impairment: Legal Aspects of Decisions to Reduce Care

H. Richard Beresford, MD, JD

Decisions to reduce care for patients with severe neurological impairment may raise legal questions. The laws of most states now authorize physicians to stop care for those who have suffered irreversible cessation of all functions of the brain ("brain death"). Where state law is not explicit, it is nevertheless probably lawful to regard brain death as death for legal purposes so long as currently accepted criteria are satisfied. Several courts have ruled that it is lawful to reduce care for patients in vegetative states, but have prescribed differing standards and procedures for implementing such decisions. The issue of whether parents can authorize physicians to reduce care for neurologically impaired children is the focus of current litigation. Implicit in this litigation is the question of how severe neurological impairment must be before parents and physicians may lawfully agree to reduce care. For severely impaired but not vegetative adults, there is some legal authority to justify certain decisions to reduce care. The issue of whether withholding feeding from a severely demented patient with life-threatening medical problems constitutes criminal behavior is now being considered by a state supreme court.

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Decisions to reduce care for patients suffering from severe neurological impairment may present difficult ethical and legal problems. Courts that have ruled on the lawfulness of these decisions have had little guidance from legislation or judicial precedent. But despite sharp debate about some rulings, a rough judicial consensus has emerged. It can be stated as follows: If physicians have determined that a patient has no reasonable prospect of attaining cognitive or other nonvegetative functions of the brain, and if physicians and the patient's informed legal representatives agree that reducing care is proper, then life-sustaining care may lawfully be withdrawn or withheld. There is no such consensus about what is lawful for less severely impaired patients, nor is there broad general agreement on what procedures must be followed to validate decisions to reduce care. This review considers neurological impairments that may justify reducing care, and discusses the impact of law on how decisions to reduce care are implemented.

Neurological Impairments That May Justify Reducing Care

Brain Death

The view that death of the brain is the equivalent of the death of the person has slowly gained acceptance. A majority of state legislatures and several courts in states without legislation on the subject have declared that,

for legal purposes, an irreversible loss of all brain functions constitutes death [28, 35]. In these states, a medical determination that generally accepted criteria of brain death have been met readily justifies stopping all forms of care. Even when the family of a patient desires that treatment continue until cardiac function ceases, a physician may elect to stop treatment. An Illinois appellate court has recently decided that physicians are entitled to remove a patient from a respirator once they have diagnosed brain death and may disregard a family's wishes that it be maintained until cardiac arrest occurs [26].

In states with neither legislation nor an explicit judicial ruling, it is probably legally justifiable to stop care on diagnosis of brain death. The common law principle that death occurs when a competent physician diagnoses it would seem to apply. Thus, in a recent appellate decision in New York (which has no brain death legislation) the court upheld a jury's finding that a criminal defendant who had caused medically diagnosed brain death was guilty of manslaughter [34]. When a physician is concerned about the lack of an explicit law or ruling on brain death, he or she may seek approval for a decision to stop care from a hospital review body. If it seems likely that the decision will provoke legal controversy, obtaining a court order is prudent.

Regardless of state law, the essential question concerning brain death is whether generally accepted medical criteria have been fully satisfied. In litigation about

brain death, disputes have centered on the adequacy of the testing that led to the diagnosis. For example, in homicide prosecutions defendants have asserted that the physicians who allegedly misdiagnosed brain death in fact killed the victims by removing them from respirators [34, 43]. Although this tactic has failed, its use highlights the importance of documenting both the criteria used for diagnosing brain death and the results of testing (including a description of the methods and results of testing for apnea) [34].

Vegetative States

The widely publicized *Quinlan* case [23] involved a young woman who had been vegetative for many months following treatment of an acute encephalopathy of undefined cause. Her examining physicians all agreed that there was little hope for neurological recovery. After the family learned of this grim prognosis, her father sought, against her physician's objections, to have her removed from a respirator. Although medical testimony at the trial indicated that she would not necessarily die if the respirator were removed [22], the focus of the litigation was on her "right to die." The New Jersey Supreme Court ultimately determined that she had such a right, that it was of constitutional dimensions, and that her father could exercise it on her behalf. Since the *Quinlan* decision, courts in Delaware [42], New York [28], Ohio [25], and Washington [29] have decided that patients in chronic vegetative states have a constitutional or common law right to the withdrawal of respirators or other life-sustaining measures. The patient in the Ohio case also had incapacitating motor neuron disease at the time of the cardiac arrest that left her in a vegetative state.

A recent ruling by a California appellate court [4] is particularly noteworthy because it involved an unprecedented criminal prosecution of physicians. At issue was the lawfulness of withdrawing care from a man who had sustained severe brain injury from a cardiac arrest during elective surgery. After a neurological consultation, his two physicians informed his family that he had a poor prognosis for neurological recovery, and on authorization from the family removed him from a respirator. When the patient did not die, fluid and nutritional therapy were withheld. He died several days later. Autopsy findings included diffuse and multifocal encephalomalacia, dehydration, and pneumonia.

At a preliminary hearing before a magistrate, all medical witnesses agreed that the patient had sustained substantial brain damage before any treatment was withheld. However, the prosecution's medical experts indicated that there was some uncertainty about the degree of recovery of neurological functions that would have been possible if the patient had received maximal treatment. The magistrate nonetheless found no "probable cause" for prosecuting the physicians, and

dismissed charges of murder and conspiracy to commit murder [32].

A superior court judge reinstated the charges [33], but they were then dismissed by a district appellate court [4]. It adopted an "omission" theory of homicide, under which a physician could be found guilty for failing to perform a duty to a particular patient if the omission caused the patient's death. The court interpreted the medical evidence to indicate that the patient "had suffered severe brain damage, leaving him in a vegetative state, which was likely to be permanent." For such a patient the court found no duty to continue what was likely to be ineffective treatment, even if the physician knew that withholding treatment would cause his death. In other words, the court seems to be saying that physicians have no legal duty to sustain the lives of irreversibly vegetative patients. The prosecution announced that it would not take an appeal to the state's highest court, leaving uncertain the weight of this case as a precedent in other courts in California or elsewhere.

Several courts have thus decided that the law does not require physicians to prolong the lives of hopelessly vegetative patients. Where they have differed is on what procedures must be followed before care is actually reduced. For example, the *Quinlan* decision [23] would require that a hospital committee review the medical determination of prognosis before life-supporting measures are withdrawn, while the *Storar* decision [28] indicates that if there is "clear and convincing" evidence that the neurological prognosis is hopeless and that reducing care would accord with the patient's wishes, care may be reduced without further oversight or review.

These nuances aside, the matter that most concerns the physician is the reliability of the determination that one who is in a vegetative state will remain that way. Law does not require absolute or statistical certainty before a prognosis is deemed acceptable as a basis for decision making. But the specific level of certainty required is not clear. Courts generally will accept into evidence an opinion based on "reasonable medical certainty" or some similar standard [9]. Then they weigh the opinions and decide what effect to give them. If a physician's determination of a hopeless prognosis is based upon a careful neurological examination, a review of published relevant studies, and consultation with those who may be more knowledgeable or experienced, then such a prognosis can be offered with "reasonable medical certainty" and may serve as legal justification for reducing care for a vegetative patient.

Congenital Encephalopathies

Each year substantial numbers of children are born with neurological impairments. These vary in severity and their full extent may not be appreciated for many

years. While some of these children may be classified as vegetative, more commonly they have diminished cognitive or neocortical functions and are labeled as mentally retarded. They may or may not have other neurological impairments, skeletal deformities, or anomalies in other systems. When severe impairments are present and parents and physicians agree that the outlook for a life of reasonable quality (however that term is defined) for the child is bleak, physicians have withheld life-supporting care [3, 11].

Actions of this nature have not, until recently, been subjects of much legal inquiry. One explanation is the law's presumption that parents act in the best interests of their children [16, 36]. From this has followed the view that the state, through the operation of its legal institutions, should not interfere in decisions parents make with respect to the medical care of their children.

The state may intervene only if it can establish, usually in the context of neglect or child abuse proceedings, that parental conduct clearly threatens the welfare of a child. Thus, a New York court ordered surgery for an infant with meningocele after finding that the parents' rejection of surgery constituted "neglect," since the child might expect a "relatively normal life" after surgery [2]. Similarly, a Massachusetts court ordered chemotherapy for a child with a curable form of leukemia over the parents' objections, since the medical evidence was that the child would certainly die without treatment [10]. But a New York court found no parental neglect in the case of a child with Hodgkin's disease whose parents had rejected conventional therapy and chosen a licensed physician who prescribed laetrile and "metabolic therapy" [27]. This last decision illustrates the power of the legal presumption that parents act for the good of their children.

The federal government has recently sought to constrain decisions by parents and physicians to reduce care for children with neurological and other impairments. Its approach has been to interpret certain federal statutes [8, 39] that provide for financial support to health care institutions as forbidding decisions that either "discriminate" against handicapped children or amount to child abuse. While the statutes themselves do not expressly forbid parents from choosing to reduce or withhold care from their children, regulations proposed under these laws empower the government to withdraw funding from hospitals or other health care institutions that tolerate allegedly discriminatory or abusive care [13, 14, 15]. The threat of this sanction presumably would cause health care institutions to ensure compliance with federal standards for the care of children.

The government's first major effort in this direction was thwarted. The Department of Health and Human Services proposed regulations, under a federal rehabilitation statute [39], that declared that the statute is vio-

lated when treatment is withheld from a neurologically or otherwise handicapped child solely because of the child's handicap [8]. The regulations required health care institutions to post notices stating that "discriminatory denial of food or customary medical care" to handicapped children is unlawful, and established a "hot-line" procedure for reporting suspected violations that would then trigger federal investigations. A federal court invalidated these regulations because they had been issued without prior public notice or opportunity for affected parties to comment, as required by a federal administrative procedure act [1]. New regulations were promptly proposed, this time allowing for public comment, but they have not yet been finalized [15].

New York's highest court recently barred a private citizen, unrelated to the parents or health care providers, from obtaining a court order requiring life-prolonging surgery for a newborn with severe neurological impairments [46]. The court held that only the state child protective service or a person authorized by a court had the standing to seek such an order. The federal government then sought to obtain the child's medical records to determine if the child had been the subject of "discrimination." A federal district judge denied this request [44], finding that there was no evidence of discrimination. The government has appealed this ruling.

Other Conditions

There are two other broadly defined groups of neurologically impaired patients for whom reductions in care may be considered. One consists of persons who are neither comatose nor vegetative but who have severe, irreversible neurological impairment and are incapable of making decisions for themselves. An example is a person in the late stages of Alzheimer's disease. The other group consists of persons who are neurologically impaired but whose cognitive functions are intact enough to enable them to decide for themselves how much care they prefer. An example is a person with incapacitating motor neuron disease or with quadriplegia after a cervical spinal cord injury. In the legal sense, persons in the first group are incompetent; those in the second group are competent.

There is limited judicial support for permitting physicians to reduce care for certain incompetent non-vegetative patients. An intermediate appellate court in Massachusetts held that an order not to resuscitate an elderly patient with Alzheimer's disease and diffuse cardiovascular disease did not require prior judicial approval if attending physicians and family agreed that the order was appropriate [20]. This finding harmonizes with the view of the California court in the *Barber* case [4] that law does not impose on physicians a duty to sustain life in all neurologically impaired patients. By contrast, an intermediate appellate court in

New Jersey recently reversed a lower court's permissive ruling [18] and suggested that removal of a feeding tube from a severely demented but not vegetative woman with life-threatening medical problems might constitute a criminal homicide [19]. An appeal of this decision to the New Jersey Supreme Court is pending. New York's highest court ruled, in the *Storar* litigation [28], that the mother of an incompetent adult was not empowered to prevent his receiving blood transfusions, even though he was terminally ill with metastatic cancer. His physicians believed that the transfusions made him more comfortable.

As a general legal principle, all persons possess a right to refuse medical treatment, even if they will die or suffer great harm as a consequence [21, 24, 30, 41]. Indeed, courts have invoked this right as the basis for permitting surrogates to choose to reduce care for neurologically impaired incompetent patients [6, 23, 29]. It would seem to follow, therefore, that a physician has no legal duty to coerce a competent neurologically impaired patient into receiving life-sustaining or other treatment and does not risk civil or criminal liability by acceding to an *informed* patient's unequivocal refusal of treatment. Moreover, forcing treatment might constitute assault and battery [17].

Implementing Decisions to Reduce Care

Once a physician has diagnosed a neurological impairment that may justify reducing care, the question whether and how to accomplish this will arise. Most states now have neither authorizing legislation nor a pertinent judicial decision. Current "living will" and related laws [37, 38] offer a basis for reducing the care of those few patients who qualify under the terms of the statutes, but do not resolve the problem of the patient who sustained severe neurological incapacity *before* any consideration was given to reducing care. In a few states (e.g., New Jersey, Massachusetts, Delaware, Ohio, and New York), judicial decisions [6, 25, 28, 29, 42] offer guidance on how to proceed, particularly for the physician who desires advance assurance that a decision to reduce care will not trigger a legal imbroglio. If there is no such guidance, the physician is left with a choice among abandoning any thoughts of reducing care, acting in accordance with perceived medical norms, or seeking formal institutional approval of a decision to reduce care. The following sections describe some "models" for decision making, derived from recent judicial decisions.

Traditional Medical Model

Testimony of physicians in the *Quinlan* case portrayed a medical tradition of adjusting levels of care to fit the condition of hopelessly ill patients [22, 23]. This includes withholding life-prolonging treatment when the only effect of treatment is to extend a life of great

misery or incapacity. Decisions of this nature are arrived at slowly and are implemented only after extensive discussions with the closest available members of a patient's family. While medical consultations are sought to assure reliability of diagnosis and prognosis, the participation of persons other than family and attending physicians is not invited. Because the process is informal and nonlegalistic, the physician has no express guarantee that he or she is invulnerable to later legal attack.

The New Jersey Supreme Court, in its *Quinlan* opinion [23], questioned the traditional model. The court considered that physicians have become so preoccupied with defensive concerns that they cannot make decisions in the best interests of patients. Thus, the court was unwilling to leave to *Quinlan's* attending physicians full discretion to decide whether or not to continue a presumptively life-supporting respirator. The physicians had opted to continue life support in the face of a dismal neurological prognosis, but the court thought that this treatment violated her "right to die." The attitude of the New Jersey court may bespeak a more general societal reluctance to allow physicians and families to make unsupervised decisions about levels of care for neurologically impaired patients. The court did not cite any data showing that the traditional medical model has led to a systematic disregard of the interests of patients, and to this author's knowledge no such data are available. Nevertheless, *Quinlan* and subsequent rulings reflect a judicial push toward a more structured decision-making process [31].

Substituted Judgment Models

INSTITUTIONAL REVIEW. To protect what it deemed a constitutional right to decline life-prolonging care, the New Jersey court in *Quinlan* prescribed a decision-making process that allows for a joint decision by physician, family, and a hospital committee [23]. Thus, if a physician determines that a neurologically impaired patient has "no reasonable possibility of regaining cognition or sapience," and a hospital committee agrees with this determination, a duly informed family member may act for the patient and authorize the physician to withdraw life-supporting measures. If this procedure is followed, none of the participants in the decision is subject to civil or criminal liability. Language in the *Quinlan* decision suggests that the hospital committee might consider ethical aspects of the decision to reduce care. But the overall tenor of the court's opinion is that the committee's function is to verify the neurological prognosis, not engage in a debate on the ethics of reducing care. The Washington Supreme Court has approved a similar procedure, envisioning that the committee ("prognosis board") will have a circumscribed role [29]. A presidential commission has also recom-

mended a procedure that includes an institutional review mechanism [36].

JUDICIAL REVIEW. In a ruling by which it authorized caretakers of an incompetent adult to withhold treatment for an invariably fatal but perhaps briefly controllable leukemia, the highest court of Massachusetts indicated that all decisions to withhold life-sustaining treatment from incompetent patients should be reviewed by a court [6]. Under the proposed procedure, a probate judge appoints a guardian *ad litem* for the patient, who investigates what form of treatment is in the "best interests" of the patient. The guardian then makes a report to the probate court and includes all arguments for continuing care. If the guardian recommends against life-prolonging treatment, then treatment can be withheld if, but only if, the probate judge concurs. The Delaware Supreme Court has proposed a similar approach [42]. The asserted benefits of a judicial role are assurance of an adequate investigation of the medical facts and an "objective" decision [5]. The implication is that a less formalistic approach may result in abuses of the interests of helpless persons, a notion that has evoked rather heated debates [5, 40].

AUTONOMY MODEL. In its *Storar* decision [28], New York's highest court rejected the doctrine of substituted judgment as a basis for decision making. In two companion cases, the court approved removal of a respirator from a vegetative patient who, before the event causing his brain injury, had clearly expressed a wish not to have his life prolonged if he were ever so afflicted, but refused to order stopping of blood transfusions for a terminally ill and profoundly retarded cancer patient whose preferences were unknowable. The thrust of these rulings is that there must be proof that the *patient* would want care reduced and that this proof cannot be supplied by the preferences of those purporting to act for the patient, be they physicians, family members, committees, or judges. Proof of the patient's preferences must be "clear and convincing." One form of proof is a carefully drawn "living will" or analogous document, but oral statements by the patient were accepted as meeting this standard in *Storar*.

The obvious limitation of this model is that it fails to cover the vegetative or otherwise severely impaired patient who has not previously expressed a preference but whose caretakers all agree on the appropriateness of reducing care. In other words, protecting the autonomy of the patient may result in what many would view as *inhumane* or *extravagant* applications of medical technology. While there is no certain resolution to this dilemma, courts have concluded that a physician is not duty-bound to sustain life in all hopelessly ill, severely impaired patients [4, 23, 29]. Thus, if a physician determines that a patient is irreversibly vegetative, there

is arguably no legally enforceable duty to sustain vegetative functions, whether or not the patient's preferences are known.

Future Directions

Legislative

The goals of preserving the autonomy of patients and protecting caretakers who try to act in the patient's best interests may perhaps be accomplished by legislation. One approach is a "living will" statute that authorizes physicians to reduce care in accordance with patients' previously declared wishes and affords legal protection to physicians who follow these directions. Several states have such laws [37], but their practical usefulness is uncertain, partly because of restrictive coverage or confusing draftsmanship [12]. Another approach is a statute that authorizes any competent person to empower a designated family member or legal representative to consent to reduction of care in specified circumstances [38]. Virginia has recently enacted such a law [45]. Finally, legislation might simply make physicians immune from civil or criminal liability if their decisions to reduce care are made in good faith and in accordance with accepted standards of medical practice [7]. This approach recognizes both the fiduciary aspects of the physician's role and the need to comply with evolving professional standards (including duties to make careful diagnoses and prognoses, to obtain "informed consent" where possible, and to employ only those treatments appropriate to a patient's condition).

Judicial

Whatever legislative developments occur, courts will remain active in this area. It may take several years before there is enough legislation to provide clear guidance on decisions to reduce care, and the legislation itself will undoubtedly require judicial interpretation in particular cases. Furthermore, the ethical, moral, and political issues inherent in decisions to reduce care are so sensitive that tidy legislative solutions are improbable. Thus, courts will continue to define on a case-by-case basis when reducing care is lawful and how the decisions must be reached. In this regard, two pending cases are of special interest. One is *In re Conroy* [19], now on appeal to the New Jersey Supreme Court. At issue is whether it is lawful to withhold feeding from an aged patient with severe untreatable dementia and major medical problems. The other is the "Baby Jane Doe" litigation [44, 46]. At issue here is the scope of the federal government's power to constrain decisions to withhold care by parents and physicians of neurologically impaired children. This case is now before a federal appeals court.

Addendum

Following submission of this article, the Department of Health and Human Services issued its new "Baby Doe" regu-

lations (Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants. Federal Register 49:1622, Jan 1984). These are less intrusive than the initial proposed regulations and seek to encourage hospitals to establish their own review procedures. The potential for federal investigations of alleged noncompliance remains, however.

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