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PART VII. LEGISLATIVE PROBLEMS OF BRAIN DEATH, IRREVERSIBLE STATES, AND THE RIGHTS OF THE INDIVIDUAL

COGNITIVE DEATH: DIFFERENTIAL PROBLEMS AND LEGAL OVERTONES

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THE PROBLEM OF COGNITIVE DEATH

The *Quinlan* case¹ raised the issue of when physicians may lawfully terminate care for severely brain-damaged adults. The question was not whether Karen Quinlan was dead, for the medical testimony clearly indicated that she did not meet existing criteria for brain death. Instead, the question was whether her physicians and family could take steps that the court thought would lead to her death. The New Jersey court made "cognition" the touchstone of decision-making. It formulated a procedure to permit withdrawal of a presumptively life-supporting respirator following a medical determination that cognition was irretrievably lost. The court thus established a legal precedent for terminating care of those adults who, while retaining vegetative neurologic functions, lack the capacity to interact with the external environment. But, although many seem to have applauded the decision, it has some disturbing features which bear mention.

To support its judgment, the court stated some conclusions that had limited evidentiary support.² For example, it flatly assumed that Miss Quinlan herself would have wished the respirator removed if only she could have perceived that there was *almost* no hope of recovery.* It concluded that she was suffering, despite extensive medical testimony that she lacked the capacity for conscious emotional experience. It suggested that her attending physicians would willingly turn off the respirator if it weren't for the fear of civil or criminal liability, despite testimony by them that this was not the basis of their reluctance. It concluded that she would not survive withdrawal of the respirator, despite medical testimony that she might survive for an indefinite period after it was removed. It assumed that the capacity of physicians to predict outcome for persons such as Miss Quinlan was well-enough developed to permit the drastic step of withdrawing life-support measures, despite the lack of systematic, statistically validated studies of prognosis in chronic vegetative states.

If this seems to be ungracious quibbling that has lost sight of the "good" the court was trying to achieve, let me move the dialogue to another level. Recall that the court was being asked to appoint Miss Quinlan's father as her guardian for the express purpose of authorizing removal of life support. To

* As of this date, Ms. Quinlan's condition has not improved. She has been in a persistent vegetative or noncognitive state for over three years despite the fact that she breathes spontaneously.—J.K.

make this appointment the court had to satisfy itself that Miss Quinlan was disabled from making such a momentous decision on her own, that the father was a proper person to whom to delegate the power of decision, and that the act of removing the respirator would not violate laws punishing homicide.

It was clear that Miss Quinlan was unable to act on her behalf, and there was ample evidence that her father is a devout and moral man who wanted to do what was best for his daughter. But the next step does not come so easily. Intentionally ending the life of another, whether by act or omission, is homicide. The court obliquely conceded this, but concluded that in order to protect Miss Quinlan's constitutional right of privacy her right to refuse medical care could only be exercised by another person. The state's interest in protecting life was not believed compelling in view of the evidence that she was a permanently noncognitive person. Therefore, the reach of the criminal law does not, according to the court, extend to decisions to end the life of the noncognitive. In other words, the noncognitive are like previable human fetuses whom the state cannot protect from abortion.

While much is done in the name of the Constitution that its framers never contemplated, the *Quinlan* decision strikes me as an uncomfortably novel expansion of a constitutional right to refuse intrusions on one's person. Permitting a delegation of one's power to exercise this right to families transmutes a notion of personal autonomy into a socially protected power to hasten or accomplish another's death. Unless there is a social compact that one who has lost cognition forfeits substantial legal protections, including those afforded by the laws against homicide, then I question the notion that the Constitution requires that families of noncognitive adults be given authority to seek withdrawal of life-support measures. Less tortuous approaches seem available if society is now convinced that ending the lives of the noncognitive is a desirable goal.

THE LAW'S RESPONSE

A New Social Compact?

Suppose for the sake of argument that the public now agrees that those without cognition should be allowed to die. If so, whatever is meant by the phrase "death with dignity" may become a generalized reality, and arguably scarce medical resources can be allocated to more deserving purposes.

As of 1947 the great judge, Learned Hand, thought the public was not ready to approve the "mercy-killing" of a blind, deaf, noncognitive child. Thus, in *In re Repouille*³ he declared:

We can say no more than that, quite independently of what may be the current moral feeling as to legally administered euthanasia, we feel reasonably secure in holding that only a minority of virtuous persons would deem the practice morally justifiable, while it remains in private hands, even when the provocation is as overwhelming as it was in this instance . . .⁴

Now, thirty years later, the climate may have changed. Advances in technology enable physicians to support the lives of the noncognitive for weeks to months, and sometimes longer. And some apparently believe that physicians abuse the technology of life-support to keep the noncognitive alive against the wishes of their families. Also, if previable fetuses no longer enjoy legal protec-

tion, then it may not be a quantum leap to deny such protection to living but noncognitive persons.

Changes in the Physician's Role

A physician is ordinarily responsible for determining the level of a patient's care, subject to the patient's right to refuse care entirely or to refuse a particular form of treatment. If society espouses the principle that physicians now have a duty to terminate life support for the noncognitive on the request of a family, and expresses the principle in the form of a legal imperative, physicians' own value preferences will no longer affect the decision of when to stop care for those who are living but noncognitive.

Some physicians might prefer this role since it places the burden of decision squarely on the family. But other physicians either may not wish to relinquish a decision-making function or may simply recoil from the act of "pulling the plug." Dissenters may, of course, avoid the conflict by withdrawing from a case. Even if this is feasible, however, it may be an unsatisfactory resolution of an already delicate, emotionally charged problem. Since both medical knowledge and value preferences are elements of decisions to reduce care, it seems important to encourage continuing participation by the original attending physician, if for no other reason than to use his or her detailed knowledge of the relevant medical facts.

Competing Values

There is no empirical basis for doubting that physicians share the same range of values as the rest of the society with respect to the care of the severely brain-damaged. The extent to which they express these values may, however, be modified by legal, ethical and peer constraints. Assuming for the moment that a physician had complete autonomy in the care of a severely and hopelessly brain-damaged patient, he or she might elect one of several courses of action. The physician might provide maximal care (including use of respirators, transfusions, feeding tubes), thereby expressing a sense of absolute duty to preserve life. Or, the physician might prescribe modified care (e.g., antibiotics but no respirator), thus indicating a belief that it is humane and practical to reduce but not eliminate care for one whose life hardly seems worth living. Or, the physician might prescribe nothing save custodial care, reflecting a judgment that there is no moral duty to maintain a patient in a vegetative state. Rarely the physician might even actively end the patient's life, convinced that there exists a higher duty to end a futile or worthless existence.

However, it is hardly likely today that physicians believe they possess complete discretion to exercise these options. Assuming that active euthanasia is foreclosed by the strictures of criminal law, the scope of potential physician-family conflict narrows to the issue of whether or not to use life-prolonging treatment. In *Quinlan*, the physicians opted for such treatment, while the family was against it. But one can readily imagine the reverse situation where the physician prefers to withhold treatment while the family seeks maximal treatment. In both situations, it is difficult to see that either protagonist enjoys a clear advantage in the moral argument. I can see no greater wrong in either

supporting life or not supporting life in this context. But I do question the merits of a rule of law that would encourage a physician to terminate life-support despite a disinclination which derives from a mixture of value preferences and skepticism about the reliability of predictions of outcome.

If there must be any bias in the law, it ought to be toward preserving life. The attending physician may be right in believing that recovery, while a remote possibility, may nevertheless occur.⁵ Also, preserving life, even though expensive and of questionable value, does not seem morally offensive. An optimal legal standard might therefore assure that physicians of living but noncognitive adults retain the primary responsibility for deciding on levels of care, a responsibility that may be shared with families where there is compelling clinical evidence that cognition is permanently lost.

Legislation

General Considerations

Any legislation that expressly allows termination of care for the severely brain-damaged would reflect a social judgment that the lives of the noncognitive do not deserve full legal protection. This judgment might rest on various assumptions. One is that it is morally right to end an inhuman existence. Another is that it is a misallocation of scarce medical resources to support life in those who won't recover. Still another is that it is simply irrational to care for those whose prognosis is hopeless.

Utilizing the legislative process has several advantages. It allows extensive fact-finding with respect to prognosis after brain injury. It permits expressions of competing moral, ethical and economic arguments. It favors consideration of a variety of strategies for handling the delicate problems at hand. If it is successfully played out, it will generate standards or rules that manifest society's views about the care of the noncognitive. If there is no societal consensus about terminating life support for the noncognitive, then either no legislation would be enacted or laws might be passed that explicitly prohibit or discourage reductions in care for the noncognitive. But even if no legislation evolves, the legislative process may serve to educate legislators and the public as to the relevant moral, medical and social policy questions.

Legislative Strategies

Permissive legislation might take several forms. One approach is to declare that it is justifiable homicide to terminate life support for a person who has permanently lost cognition. Those who view "pulling the plug" from persons who are not medically and/or legally dead as something other than a homicidal act might object to such a law, for it implicitly concedes that such conduct is homicide. A less evocative approach might be to declare that no one shall be prosecuted for homicide who terminates life support for a noncognitive person. This makes no concessions about the nature of the act, but nonetheless excuses it.

A way to skirt the homicide issue is to expand the definition of death to include permanent loss of cognition. Such a law, while seemingly straightforward, would nevertheless generate substantial difficulties. What constitutes a

permanent loss of cognition would require careful definition. The issue of how to handle the patient who has lost cognition, yet has intact cardiorespiratory function, would have to be faced. And, determining a precise time of death, which often has important legal and social implications, might prove even more taxing than deciding when brain death has occurred.

Legislation might effectively codify the *Quinlan* decision by providing for a determination of prognosis by a committee and, if recovery of cognition is deemed hopeless, a formalized agreement between family and physician to terminate life support. If the statutory procedures were followed, no liability would attach to the various participants in the decision. While potentially cumbersome, this approach might promote extensive dialogue and shared responsibility with respect to a hard decision. Whether it gives too much visibility to the decision-making process or may actually encourage resort to termination of care is open to debate. A variation of this mode is to mandate that family and attending physician obtain a court order to terminate care after the prognosis committee has concluded that recovery of cognition is hopeless and the family and attending physician have concurred about ending life support. Many procedural formalities could be included in such a statute.

"Living will" laws might be adapted to allow someone other than a patient to authorize termination of life support. But even if a statute like that recently enacted in California⁶ were amended to allow such a delegation of authority, it would not resolve the problem posed by the *Quinlan* case. The current California law requires not only a formal written statement by a person, while competent, that he or she does not want "life sustaining procedures" if a "terminal condition" eventuates, but also evidence that death is imminent but for the life support measures. The evidence in the *Quinlan* case did not clearly establish that death was imminent but for the use of the respirator.

Removing from a "living will" statute the requirement that death occur promptly upon withdrawal of life support would permit discontinuance of respirators for those noncognitive who may survive for an appreciable period thereafter. If this approach is chosen, the statute should explicitly declare that it covers withdrawal of technological support from the noncognitive. This would reflect a legislative recognition of the fact that patients in vegetative states often retain spontaneous respiratory functions.

Nonlegislative Options

Because each of the preceding legislative changes would require an agreement among legislators that the noncognitive person is to be denied certain legal protections, it is highly doubtful that major enactments are about to occur. The difficulties of gaining acceptance of "brain death" laws in some states emphasize this.

If no legislation emerges, physicians and families—unless they reside in New Jersey—will have scant legal guidance for decisions about care of the noncognitive. Every party to such a decision may therefore allow the possibility of civil or criminal liability to affect their judgment about the rightness of withdrawing care. This may have the potentially salutary effect of generating consultations with knowledgeable medical and ethical advisers to establish a sound factual and moral basis for whatever decision is made. But it might also rigidify the conduct of the parties. They might retreat to intractable positions

that are more self-protective than cognizant of the interests of the afflicted patient. This would only increase the likelihood of a legal confrontation, and bring the courts more and more into the decision-making process, I, for one, do not believe that this is a desirable role for the judiciary.

CONCLUDING REMARKS

The testimony in the *Quinlan* case reminded the public that physicians and families sometimes make value-laden decisions about care of the severely brain-damaged. Since prognosis is the most factual element of such decisions, it is the most amenable to analysis. But even prognosis is only an estimate of future probabilities based on whatever present data are available. If these data are less than conclusive, as is the case when predicting the chance of recovery of some noncognitive persons, prognostication becomes distressingly speculative. Where such imprecision exists, a restrained approach to withdrawing life support seems appropriate. Unless a physician has clearly misinterpreted factual data which compel the conclusion that maximal care is futile, I question whether society should attempt, through the courts or otherwise, to overrule his or her judgment. That the judgment might also involve an assertion of personal values or an anxiety about the reach of the law does not, in my mind, dictate that we diminish the physician's role in determining what level of care to provide.

Protecting the physician's discretionary power to prescribe care may, in the long run, provide the flexibility that is needed for informed and humane decisions about the proper level of care for noncognitive persons.⁷ The physician is in the best position to assemble and evaluate, with the aid of his or her consultants, the pertinent medical data. Once the data are fully analyzed, some predictions about outcome may be possible, although the degree of certainty may vary. In some situations, particularly after current studies⁸ of outcome in vegetative states are completed, the physician may be able to venture a highly certain prediction of nonrecovery. Given a great degree of certainty about prognosis and a family's clearly articulated desire to reduce care, a *Quinlan*-style disagreement should not occur. Legislation which in some way insulated such private decision-making from legal inquiry might do much to relieve the agonies of the decision-makers about the propriety of their conduct and, if properly drawn, need not bias decisions for or against reductions or withdrawal of care.

Professor Joseph Goldstein of Yale Law School has recently advocated restraining interventions by the state into parental decisions about the care of children whose lives seem not worth living or who have little prospect of growth to a normal adulthood.⁹ He would deny the state any role in a life/death decision where there is no proven treatment, or the parents are faced with conflicting medical advice, or there is less than a high probability that treatment will improve the child's prospect for a normal life. In his words:

... Precisely because there is no objectively wrong or right answer, the burden must be on the state to establish *wrong*, not on the parent to establish that what is right for them is necessarily right for others.⁹ (p. 655)

His analysis of the *Quinlan* case suggests that he would also give families of noncognitive adults a major voice in decisions about care, because families are at least as capable of weighing the value questions as are physicians or judges.

Although he apparently would make this a principle of constitutional law, some of the legislative approaches outlined above have the advantage of both explicitly codifying a societal consensus (assuming it exists) about cognitive death and protecting joint decision-making by physicians and families. Leaving the issue as one of constitutional interpretation would probably promote continuing resort to the courts on a case-by-case basis. This would needlessly encumber already hard decisions.

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DISCUSSION

J. FRAPPIER (*Jefferson City, Missouri*): I supported legislation on brain death following the suggested outlines of Capron and Kass in 1976 and the ABA in 1977. We did not make it with either one of them. We have always taken the position that Blacks' Law is our problem and interferes in relationships between doctors and the patients and families. Would you comment on the legal situation in a state with Blacks' Law in terms of making a diagnosis of brain death?

BERESFORD: Professor Capron is the authority on this. There are a number of states in which physicians have made the decision. Remember, the subject I have discussed is different from brain death. I am evaluating the next generation of problems, which involve cognitive death, so anything I say related to your question does not pertain to the issue of cognitive death but to brain death. In fact, in some states physicians have withdrawn medical care in patients in whom they deem it appropriate on medical grounds. The criteria used are related to absence of brain function and brain death. This occurs despite the lack of protection of a statutory "umbrella." This happens in New York as well as in other places, I am sure. I know of no murder prosecutions against physicians. The issue of murder has come up indirectly when a person is being

charged with the murder of the brain-dead individual. The defense has interposed that it was the physician who removed the respirator and by removing the life-support system was the actual killer. The courts have thrown out that notion as well. In practice physicians are using brain-related criteria in determinations of death, even where there are not umbrella statutes. Of course, I do not know how often they are doing this. There have been some civil suits in one form or another, all of which have been unsuccessful so far, I believe.

GRENVIK: For two and a half years at the Presbyterian University Hospital in Pittsburgh we have used a program similar to the one outlined in your presentation. In our intensive care unit, we have 900 admissions per year and about 8 or 9 percent of those patients are finally categorized as so-called "no extraordinary measures" patients. We have an agreement in all of these cases with the next of kin and the family, but we do not have formalized papers that they sign. Two things are done in each case: a progress note is entered into the medical record, indicating that discussion has taken place with the family and that agreement has been reached, and an order is written in the order sheet. Do you see any legal problem with this procedure?

BERESFORD: Are you referring to brain-dead or to noncognitive patients?

GRENVIK: I am not referring to the brain-dead patients. I mentioned the term "no extraordinary measures," which refers to the nonaware patients, the hopeless cases, not the brain-dead ones.

BERESFORD: A potential problem exists, but you have to remember that the way any legal action comes about is that the District Attorney in the jurisdiction has to decide whether this was a case that he thought merited prosecution, as a homicide or as manslaughter. This is one advantage of allowing people in responsible positions to have some discretion. However, some of those acts may technically be homicide, although one can introduce the element of moral culpability as a necessary foundation for a homicidal charge.

GRENVIK: We are aware of that risk. The question is: Do you deem it necessary to have a consent form for them to sign?

BERESFORD: I am a nonbeliever in forms as a general rule.

A. VAN TILL (*The Hague, The Netherlands*): I have one remark to make and two questions to ask concerning a proposition for legislation. If an individual with irreversible loss of cognition were declared dead, which could be possible, then one of the questions that can be asked is: why should the respirator be shut off? The irreversibly comatose person who has been labelled dead could be used for teaching, experiments, or organ transplantation. Such practices are not unthinkable. Therefore, legislators should be aware of this possibility and seek to eliminate it.

My first question is: what are the chances that the New Jersey Supreme Court decision in the Quinlan case will be accepted as legal procedure in other states? Second, how far does the legal basis go in the United States for parents or legal representatives to have or be given rights by a court to decide about life and death of their children? Could children possibly be given rights to decide about life and death of their parents in reverse situations?

BERESFORD: These are difficult questions to answer. In response to the question about the right of parents to refuse life-saving care for their children, there is a "mixed bag" of cases, which are usually related to transfusions for the children of Jehovah's Witnesses, a religious group in this country that rejects the use of blood. The courts have gone both ways in this, so the situation is a jumble. As far as children being surrogate decision-makers for parents, the

issues are the same as in the Quinlan case, where there was an adult patient and an adult parent.

I think it is highly doubtful that the Quinlan case will become the law of the land. My criticisms of the Quinlan decision are relatively mild compared to the criticisms of some who believe the decision to be an artistic legal product. I believe that many people are intuitively happy with the decision. It is really a social policy question, and I could not begin to predict what gravitational effect this sort of decision will have in other states.

CAPRON: I think that the cases involving the refusal by parents of transfusion for their children on religious grounds have gone pretty much one way; that is, that parents do not have that authority. As for people who are allegedly incompetent choosing for themselves, the case lore is a complete muddle. Concerning parental decision-making, the courts have gone so far as to say if a Jehovah's Witness is pregnant and is at risk of hemorrhaging etc., during the birth process, and refuses permission to have transfusion, the doctors have to decide whether a transfusion is necessary to save the child's life. The only time a physician can overrule the parent's decision in this case is during the birth process. This is an indication that, as the court said in one famous decision, parents have the right to any beliefs they want, but they cannot make martyrs of their children for those beliefs.

BOSHES: I am particularly appreciative of Dr. Beresford's statements. For those of you who have not read it, I recommend your reviewing his commentary written some months ago in the *Annals of Neurology*. It is a careful and very scholarly analysis of the Quinlan decision, in which he points out the inherent danger of this decision.

Universal application of the results of the Quinlan decision could result in great abuse. One could go through hospitals for the mentally defective or through "coma wards" where there are patients who have been lying in a state of coma for up to 18 years. Many of these patients are in a noncognitive and nonsapient state.

None of these patients could meet Professor Joseph Fletcher's criteria of humanhood. All of these people could be "disposed of" by not feeding or not treating them, if we are to open up this Pandora's box. The question remains: Are we going to be pragmatists or are we still going to remain moral physicians?

S. VERNON: I praise Dr. Beresford for placing the burden of responsibility and decision-making on families, but I would have been even more gratified if I could have heard some plea for making a physician, no matter how competent or moral he may be, less vulnerable. Could this be done by having anyone who wants to attack him (by means of) law suits do so by the placement of a fee with a clerk of the court.

BERESFORD: I do not know if that covers the whole question of professional liability. This is one area I won't try to take on.

KEENE: How comfortable would you feel about a judicial or medical decision to remove life-support systems in a case in which a patient gave ample evidence beforehand that he desired removal of life-support systems if he should enter into a permanent noncognitive state?

BERESFORD: I would be more comfortable; and I think the Quinlan court would have been more comfortable. The query relates to the medical prognosis. The medical standard of brain death as developed by scientific investigators demands that we not make any mistakes at all. We have to be 100 percent certain. We do not want to declare somebody dead who might recover. So the

same rigid scientific criteria seemed necessary to withdraw care from patients in noncognitive states, such as Karen Quinlan. The fact that the patient has said that he wants to have care withdrawn if this state of brain dysfunction eventuates would make decision-making much easier if one gets around the prognosis issue. But how good is our prognosis when it deals with noncognition as opposed to brain death? At this stage we are becoming more accurate. As more data are being produced, the prognosis in these situations is becoming more reliable. However there are few grounds for the physicians interposing himself against a rush to establish the right to die, etc.

NESBAKKEN: I enjoyed your presentation, Dr. Beresford, but I object to its title—Cognitive Death. Could you please find another word to use instead of *death*, just in this context? Death is one definite thing based on the total destruction of the brain. Cognitive death may cause difficulty in understanding the topic, at least among laymen.

BERESFORD: That opens up the philosophic conception. I accept your criticism. It is a reasonable one and it is almost by default that I use the word death because the conceptualization of this is very difficult.