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The Persistent Vegetative State: A View across the Legal Divide

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Praise for Fred Plum can take many forms: for pedagogical dynamism, for depth and breadth of contributions to neurology and neuroscience, for sure-handed guidance of a department that has infused neurology with today's and tomorrow's leaders, and for a truly uncanny ability to fan a drive to excel in those he has touched. Mindful of his admonition to be substantive in what one says and does, my praise will embody a few reflections on the enduring legal and social impact of the "point of view" he and Bryan Jennett authored for the journal *Lancet* in 1972.[1]

THE *LANCET* PAPER

Recognizing the need for an acceptable term to describe patients who are "neither unconscious nor in coma in the usual sense of these terms," Jennett and Plum proposed the term "persistent vegetative state" (hereinafter PVS). It was of course not the choice of label that made their effort important—although it bears noting that, to this day and despite various attempts to come up with a better descriptor, the term enjoys general acceptance in both medical[2] and legal[3] forums. What Jennett and Plum accomplished is a particularly vivid reminder that some severely brain-injured persons may have "wakefulness without awareness." Such individuals may exhibit coordinated motor responses after noxious stimuli or even spontaneously, and may utter sounds, move their eyes, grimace, smile, or even swallow food or liquids placed in their mouths. Yet it is impossible to demonstrate that they respond in a discernibly conscious way to specific auditory, visual or other sensory inputs. In short, there is, despite an apparent wakefulness, the "absence of any evidence of a functioning mind which is either receiving or projecting information."[1]

The fact that subcortical and brain-stem structures remain functional allows prolonged survivals if caregivers attend to nutrition and hygiene. This potential for indefinite survival, observed Jennett and Plum, "presents a problem with humanitarian and socioeconomic implications which society as a whole will have to confront."[1] The problem is indeed profound and has generated—and will continue to generate—practical and conceptual dilemmas for physicians and the legal system.

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THE *QUINLAN* LITIGATION

The PVS became a center of legal controversy in 1976 when Fred Plum and others testified that Karen Quinlan was in a PVS and would remain that way. What the court failed to hear—or at least failed to grasp—was his additional testimony that her survival was not necessarily dependent on use of a mechanical ventilator. Whether this judicial misconception affected the ultimate decision by the New Jersey Supreme Court is speculative. However, both the trial court and the state supreme court assumed that removal of the ventilator would shortly lead to her death.

The judiciary in *Quinlan* conceived its role as determining the lawfulness of allowing Ms. Quinlan to die by reason of removal of her life support. To this end, it sought assurance from medical experts who testified that she was surely permanently unconscious, and heard testimony from her father, physicians, theologians and others about the moral basis for authorizing her father to request removal of the respirator. Having appraised this evidence, the New Jersey Supreme Court ultimately ruled that if her physicians agreed there was "clear and convincing" evidence she was permanently unconscious and a hospital ethics committee concurred in this prognosis, her father could, under the legal doctrine of substituted judgment, lawfully exercise her constitutional right of privacy to refuse the ventilator.[4] As many readers know, the ventilator was then discontinued and Ms. Quinlan survived nearly 10 years—as Fred Plum might have predicted. A recent report in The New England Journal of Medicine described the neuropathological findings in her brain.[5] Although cortical scarring was present (especially in parietal and occipital regions), the most extensive scarring was in the thalami. Basal forebrain, brain stem and hypothalamus were largely intact.

In rationalizing its decision, the New Jersey court opined that allowing Ms. Quinlan to live in a PVS was akin to asking her to "endure the unendurable."[4] It hypothesized that if she were granted a brief lucid interval to gauge her plight, she might readily conclude that continuing survival was something she would choose to forego. The court thus viewed PVS as a condition that at least some sapient persons would regard as equivalent to death. Consistent with this view, the court discounted the assertion of Ms.Quinlan's attending neurologist that his reluctance to remove the respirator stemmed from uncertainty over whether this was a medically appropriate action. The court—without supporting evidence—simply assumed that his reluctance reflected fear of adverse legal consequences. In other words, it must have seemed axiomatic to the court that an informed physician would not allow a commitment to protecting human life to engender treatments that would do no more than extend a life of perpetual unawareness.

Responding to concerns that it was authorizing euthanasia, the court offered two defenses. First, it declared that if Ms. Quinlan died after removal of the ventilator, the cause of death would be the brain disorder that caused her to be in a PVS, not the withdrawal of support for respiration. Second, even if there were a causal link between death and removal of treatment, the court viewed any "homicide" as justifiable because it would implement her constitutional right to decline medical treatment.

LITIGATION AFTER *QUINLAN*

Since the decision in *Quinlan*, many courts have approved requests to end life support for persons in PVS.[6-8] Although dissenting judges have occasionally vociferated about the devaluation of "life" that these decisions imply,[8] a consensus has developed that permanent unconsciousness is a cogent justification for ending life support. Legal controversies now tend to center on whether life support can lawfully be withdrawn from individuals whose preferences are unknown or unknowable, on whether severe neurological afflictions with preservation of rudimentary awareness should be approached in the same way as PVS, and on whether a legally meaningful distinction exists between removal of a mechanical life support and removal of fluids and nutrition. Of these, the first two draw the most attention and will be highlighted in the brief discussion that follows.

The Conroy *Litigation*

Several years after the *Quinlan* decision, the New Jersey Supreme Court was asked to rule on the request by the nephew of the severely brain-injured Claire Conroy to remove her feeding tube. Ms. Conroy was not in a PVS—her physicians had detected modest behavioral responses to sensory stimuli. She was, however, severely demented, incontinent, and bedbound in a nursing home and had no prospects for clinical improvement. Her wishes about use of the feeding tube were unknown, but her nephew believed that removal of the tube was consistent with her previously exhibited attitudes and values. After prolonged litigation, the court ruled—after her death—in *In re Conroy*[9] that the medical facts did not justify granting the nephew the authority he sought. However, the court did prescribe a procedure for use in nursing homes that would permit withdrawal of life support from severely impaired residents whose preferences are unknown.

Under the *Conroy* court's formula, life support could be stopped if there is "clear and convincing" evidence that the burdens of sustaining life exceed the benefits of continuing survival. In making this "objective" determination, the court indicated that physical pain is the operative burden and that proof of intractable pain is necessary before the burden of survival should be taken as outweighing the benefits of remaining alive. An individual would thus need enough awareness to experience demonstrably intractable pain before life support could be stopped under this "objective" prong of the *Conroy* formula, a requirement that obviously excludes individuals in a PVS.

The Cruzan *Case*

The primacy of autonomous choice in end-of-life decisions is exemplified in the U.S. Supreme Court's recent decision in *Cruzan v. Director*.[3] The core of the dispute between family and caregivers was not over whether Nancy Cruzan was in a PVS. The testifying neurological experts largely agreed on that point, and the Court exhibited no qualms about the idea that a competent individual might prefer death over life in a PVS. However, the Court upheld a Missouri statute that required "clear and convincing" proof that this was indeed Ms. Cruzan's choice. It would not concede that being in a PVS is in itself a lawful justification for ending life support. In other words, the Court was unwilling to presume that Nancy Cruzan—or anyone else for that matter—would actually choose to reject a feeding tube in such a circumstance. Although there are data on which the Court could have relied in adopting such a presumption, its refusal was consistent with prevailing law.[10] The Court's decision in *Cruzan* thus underscores the powerful impact of the autonomy principle in deliberations about whether to continue life support for individuals in PVS or with other severe neurological impairments.

The Supreme Court did not say that it is unlawful in all circumstances to end life support for individuals in a PVS if their wishes cannot be ascertained. But it did indicate that a state's interest in protecting the life of its citizens empowers the state, in a constitutional sense, to require convincing proof that ending life support is what the afflicted person would have chosen, whether by written advance directive or by unambiguous oral statements. In a separate opinion, moreover, Justice Scalia even suggested that a state legislature could, in the interests of upholding the preeminent value of life, bar removal of life support from those in a PVS—even if this constraint is contrary to their autonomously expressed wishes. These threads suggest that the Court will be inclined to defer to democratically enacted laws concerning decisions about removal of life support. If this interpretation is correct, state lawmakers should have considerable leeway in developing standards and rules for end-of-life decisions affecting individuals with severe neurological impairments. It thus seems appropriate to consider non-autonomy based justifications state lawmakers might use to guide their policy choices.

JUSTIFYING LIFE-ENDING DECISIONS

PVS as Death

As Plum and colleagues have shown with positron emission tomography, cerebral blood flow and metabolism can be profoundly impaired in the PVS.[11] Law professor David Smith has used this information to buttress an argument that PVS should be treated for legal purposes as equivalent to brain death.[12] He is not the first to propose that a permanent loss of consciousness be regarded as a death of the human person, and that ethical and legal rules should be modified to take this into account, but he is the first to rely substantially on advances in neuroscience to reorient societal attitudes about the relationship between consciousness and human life. Although his proposal has not attracted wide support, it challenges the many who readily accept the notion of brain death to explain why the two types of permanent unawareness, brain death and PVS, should have different legal connotations.

An obvious response is that, in the present state of the art of neurology, brain death is an absolute indicator of permanent unconsciousness, whereas a diagnosis of PVS carries with it a small but somewhat quantifiable chance that some awareness will return.[2,13] Another response might be that using consciousness as the measure of life risks indeterminacy because of the difficulties that inhere in arriving at an agreement on definition of the term,[14] even among physicians.[15] It is arguably easier to rely on a demonstrated presence or absence of brain-stem functions as the measure of human life. In this construct, the concept of mind plays no role in the definition of life; it is the brain stem that counts, no matter what the state of the neocortex.

PVS as Diminished Life

Even if the PVS is not the same as death, there is an emerging consensus that traditional constraints on decisions about life support apply less stringently to persons in a PVS than to persons with lesser impairments. For example, the New

York Do Not Rescucitate law includes permanent unconsciousness as one of four grounds for writing a DNR order,[16] and the federal child abuse law would allow ending life support for neonates who are "irreversibly comatose."[17] Also, the *Quinlan* court explicitly declared that the state's interest in protecting life wanes in proportion to the prognosis for regaining awareness.[4] In other words, not all lives are equal when it comes to applying protective legal and ethical rules. The slippery slope concerns here are obvious. Although these concerns should help to constrain temptations to expand the definition of diminished life, they also probably assure that the legal system will continue to be called on to resolve uncertainties about the rightness of withdrawing care from some individuals with severe neurological impairments.

PVS and the Beneficence Principle

A professional obligation of physicians is to provide treatments that help their patients and withhold treatments that burden or do not help. For PVS and other severe neurological impairments, the universe of demonstrably helpful treatments is small once adequate nutrition and hygiene have been provided. Yet is is also difficult to envision treatments that are burdensome to such individuals. They are, by definition, too neurologically compromised to experience quantifiable suffering. Thus, applying a traditional benefit/burden analysis to evaluate what care to provide or withhold is not a fruitful enterprise. If we take into account the suffering of caregivers or the strength of public attitudes about what ought or ought not to be done, then it might be possible to arrive at a calculus of benefits or burdens. However, this would have little to do with the interests of the afflicted individual unless, for example, he or she had once strongly expressed a wish not to be a financial or emotional burden on others. In this scenario, it might be defensible to hold that prolonging survival is indeed a burden that could be weighed against the contestable benefit of remaining alive.

PVS and Resource Allocation

The social costs of caring for individuals with severe neurological impairments are already substantial. Moreover, for the near term at least, developing treatments are more likely to extend life span than to achieve meaningful neurological improvement. The polity therefore faces increasingly hard choices about how many resources to allocate to persons who will never improve or achieve any capacity for social participation. One option is to do as Oregon has done: formally and explicitly establish categories of illnesses or individuals to whom few or no public resources are allocated.[18] This sort of rationing is contentious anywhere, but especially so in a society as wealthy as ours. Nevertheless, the current drive to constrain health care costs through greater reliance on market forces and reduced public expenditures will almost inevitably result in fewer resources being available to care for those with severe and permanent neurological impairments.

The legal system in the United States affords no constitutional or other formal entitlement to health care—although federal and state legislation do offer a variety of safety nets—and the public seems quite tolerant of the fact that millions of citizens lack health insurance or secure access to minimally adequate health services. In this cultural setting, it is not difficult to foresee a growing public willingess to skimp on care for the severely brain injured. A simple ethical justification for this attitude is that health resources are finite and must be expended where they do the most good. Individuals with severe neurological impairments arguably have a weak claim on these limited resources because they have so little to gain from treatment. Whatever claim they have would rest on the principle that all human lives have instrinsic value and that a moral society will expend a decent minimum of resources to sustain those lives. Yet, as we have seen, the judiciary and much of the public have accepted the proposition that society's obligation to the severely brain injured does not include use of all available life-extending resources. Against this backdrop, it may be worthwhile to look at the role of clinical neurologists in decisional processes that could eventuate in ending life support for the severely brain injured.

NEUROLOGISTS AND PVS

Formal Ethical Standards

The American Academy of Neurology holds that it is ethical to withdraw life support (including fluids and nutrition) from a patient in a PVS, provided the diagnosis is secure and there is evidence this accords with the patient's wishes.[19] The Academy's position rests on the considered belief that the PVS, as defined by Jennett and Plum, is diagnosable and that its salient feature is an irreversible loss of awareness. It further reflects an assumption that consciousness is what confers special value on human life.

In a sense, the Academy position on PVS is inconsistent with its later declaration that the taking of vital organs from anencephalic infants for purposes of transplantation is unethical because it violates the "dead donor" rule.[20] Individuals in a PVS and anencephalic infants are both permanently unconscious, and it is arguably illogical to suggest that actions which cause their deaths—removal of a feeding tube or removal of both kidneys—are ethical for one but not the other. Several counterarguments can be raised, however. The most straightforward is that the Uniform Anatomical Gift Act,[21] which regulates organ transplantation, requires that heart-beating donors be brain dead before their organs can be removed. Also, surgical removal of organs is a far more invasive, coarse, and immediate cause of death than removal of a feeding tube or respirator. Moreover, society has always treated newborns with a special solicitude and using them as organ sources, even for the most altruistic of purposes, may be too crass to contemplate.

Whatever the inconsistency between the two statements, they stress the need for careful and rigorous assessments of severely brain-injured individuals and concurrent sensitivity to legal and social overtones. In these respects, the statements recognize that both clinical expertise and enlightened citizenship should be brought to bear, a call that Jennett and Plum heralded in the *Lancet* paper. However, conflating applications of neurological expertise with ethical and social policy choices can be problematic.[22]

Without offering a definition of consciousness, the Academy's position statement on the PVS declares that permanent unconsciousness can be reliably identified. A recent comprehensive review of published studies[21] lends support to this view. It cites two types of evidence. One type constitutes the accumulated experience of neurological clinicians applying established criteria for the diagnosis of PVS, coupled with outcome data which reveal that individuals vegetative for longer than one year rarely regain awareness. The second type of evidence derives from *in vivo* neuroimaging and postmortem neuropathology. The imaging studies demonstrate profound cortical hypometabolism in PVS, and autopsy studies typically reveal extensive neocortical injury. It thus appears that neurologists can offer a tenable diagnosis of PVS by applying appropriately rigorous clinical standards, but it is less clear that they can offer expert guidance to those who must actually decide whether to withdraw life support.

Boundaries of Neurological Expertise

Assume for the moment that an accurate diagnosis of PVS can be made. Does it then follow that neurologists' opinions about what ought to be done should be given special weight by families or other decision makers? For example, can neurologists confidently assure decision makers that individuals whose eyes are open and who move and make sounds nevertheless cannot experience pain or pleasure? Can they accurately predict how long the individuals will survive? Can they communicate a sense of what it is to be "unconscious"? Can they inform decision makers as to what constitutes an appropriate allocation of resources for one in a PVS? If not, the neurologist's role appears narrow, albeit pivotal. It is narrow in the sense that the ethical issue of whether life support *ought* to be stopped must be resolved by others (for example, families, primary providers, courts). It is pivotal because the issue of whether to end life support is not ripe for discussion until there is no more than trivial uncertainty about diagnosis or prognosis.

If making a diagnosis of PVS is indeed the principal contribution neurologists can make in resolving the ethical and legal dilemma, the reliability of the diagnosis assumes overriding importance. The 1994 review,[2] noted above, concluded that recovery of consciousness in adults who have been vegetative for more than one year is "exceedingly rare." The few persons who did regain consciousness after that interval, including one who had been vegetative for 36 months, were totally dependent and had severe residual neurological impairments. A more recent report in the same journal described a patient who regained consciousness after 17 months in a vegetative state.[13] After reviewing available data describing recovery of awareness after one year in a vegetative state, the authors estimated that the probability of regaining some awareness was 14 percent. If this figure is accurate, the question then emerges as to how certain neurologists can be when they offer their opinions to families, primary providers, ethics committees or courts.

Available data clearly would support an opinion that an adult who has been vegetative for more than one year will *probably* not regain consciousness. These data may also amount to "clear and convincing" evidence, a more exacting legal standard. However, they do not appear to support an opinion that meets the most rigorous legal standard of "beyond a reasonable doubt." This standard requires something akin to moral certainty about the accuracy of an opinion. At minimum, a neurologist could still testify with moral certainty that a person in a PVS for more than one year will have severe neurological disabilities and will be incapable of independent living, whether or not consciousness returns.

Decision makers may or may not rely on neurological opinions that rest on less than moral certainty. They could, for example, accept opinions based on the sort of probabilities clinicians ordinarily apply in their clinical practices. These seldom add up to moral certainty, and may not even meet a "clear and convincing" test of legal probity. On the other hand, where reliance on an opinion may lead to a decision to cause or hasten the death of an individual, decision makers may insist that opinions rest on a moral certainty as to their accuracy. These considerations have clear significance for neurologists asked to venture opinions about individuals in PVS. They should try to determine what standard of certainty they are expected to meet, and should self-critically evaluate whether their opinions will satisfy that standard. Since the data available to support an opinion are somewhat "soft," the challenge may be daunting; however, trying to sidestep the challenge could deform an ethically sensitive decisional process that calls for the best that neurological clinicians have to offer.

CONCLUDING REMARKS

The debate over what justifies ending life support for individuals with severe neurological impairments will continue. Wider use of advance directives and a growing willingness of lawmakers to countenance autonomous life-ending choices will temper the debate. However, the public is likely to remain uneasy about slippery slopes and about threats to the sanctity of life it may perceive in efforts to calibrate legal and ethical protections by reference to the status of the neocortex. In this context, the contributions of Fred Plum stand out. By stressing the defining role of higher cortical functions for the human condition and by challenging clinicians, lawmakers and others to engage over the meaning of irretrievable loss of these functions, he has both framed and richly informed the debate.

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