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by

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Introduction

We re-examined the Quinlan case in light of unfortunate subsequent developments, especially the "Right to Die" movement which has swept the country like a pestilence in the past ten years. We believe that the only just and heroic stance in her otherwise miserable case history was that made by the medical and nursing attendants who tried to protect her from pro-death enthusiasts. All the others, the Court, the *amicus curiae* of the Roman Catholic Church, the so-called experts on life and death were in a fog of uncertainty about fundamental medical issues and apparently had little or no conception of the social consequences of their recommendations and decisions. The family, accepting the current rage to declare brain death in all with any significant impairment of cerebral function, were blindly led by the blind.

We dare to quote what Adolf Hitler once said in one of his rambling monologs: "... some must perish so that others can live."¹ Yes, current so-called "ethics" demands "justice for all,"² not for the individual patient (especially if he or she is a social burden). We say, not only justice but happiness for others purchased by the sacrifice of a victim, a still-*living* victim, a victim of personal misconduct perhaps, but often only a misfortune. Karen was a profoundly disabled person, but wasn't she still a person entitled to protection? Costs are not mentioned in the Quinlan case, but they must have been considerable: the last ten years of her life were in a nursing home. The most recent bioethical thought and legal judgements would indicate that "cost-effectiveness" can justify setting aside the protections of the Americans with Disabilities Act.³ The court's decision in the Karen Quinlan case was perhaps a prototype of such legal discrimination. Her case is a paradigm of what could happen to everyone not measuring up to society's standards of what constitutes "normality."

The pages of the *Journal of the American Medical Association* and the *New*

England Journal of Medicine are neither holy writ nor the last word on any subject. But they are too often treated as such. They have a definite and very expedient political agenda regarding death and euthanasia. Dissent is often excluded. As an example of the pro-death bias of the editorial policy of the *Journal of the American Medical Association*, we mention the publication, in 1988 of "Its Over, Debbie,"⁵ an anonymously written article describing the killing of a supposedly terminal cancer patient by the author, a hospital resident.

We would present here a different picture of the Quinlan debacle. We humbly request the right to be heard before this culture of death envelops all of us in a gloomy and desperate future.

The Re-examination

"On the night of April 15, 1975, for reasons still unclear, Karen Quinlan ceased breathing for at least two fifteen minute periods."⁶ She died ten years after her cardio-respiratory arrest, having never regained consciousness. The cause of her unconsciousness was never clearly established.

The case report in the *New England Journal of Medicine* [hereafter case report] indicates Karen had ingested alcohol and prescription sedatives.⁴ It has been suggested that she may have taken aspirin⁷ and even may have fallen.⁸

According to the case report, Karen was resuscitated and had resumed spontaneous breathing and normal vital signs within an hour. The following 12 hours witnessed sequential improvement as she responded to pain, coughed, and gagged. She moved all extremities spontaneously and opened her eyes in response to auditory stimuli. A tracheostomy was performed on the second day to facilitate the ventilatory assistance she required.⁴

The experts testified that in addition to being comatose, Karen was in a "chronic and persistent vegetative state," having no awareness of anyone or anything around her and that she existed at a primitive reflex level. They admitted that she evidenced some brain stem functions (ineffective for respiration) and exhibited other reactions one customarily associates with being alive, such as moving, reacting to light, sound and noxious stimuli, blinking her eyes, and the like. "She grimaces, makes stereotyped cries and sounds, and has chewing motions. Her blood pressure is normal."⁶

Karen's father, Joseph Quinlan, petitioned the New Jersey court to be appointed legal guardian of his adult daughter. He sought the express power to authorize the termination of all extraordinary procedures sustaining Karen's life, since her attending physicians, who were guided by "pertinent medical standards and practices," were precluded from removing her respirator.⁶

The trial court, in its pretrial conference order (R. 4:25—1 et. seq.) of September 22, 1975, entered certain "factual and legal contentions," including as follows:

1. Legal and Medical Death. (a) Under the existing legal and medical definitions of death recognized by the State of New Jersey, Karen Ann Quinlan is dead.

This contention of "brain death" was discarded during trial by a stipulated

amendment that "Karen Ann Quinlan is presently alive."⁶

In its opinion expressed in *In the Matter of Karen Quinlan, An Alleged Incompetent*, the New Jersey Supreme Court (hereafter the Court) described Karen as being in "a debilitated and allegedly moribund state," and described her posture as being "fetal-like and grotesque."⁶

The experts appearing before the Court testified that Karen could not survive without the assistance of the respirator. They indicated there was strong likelihood that she would die soon after its removal. The Court noted that "No physician risked the opinion that she could live more than a year and indeed she may die much earlier."⁶

The Court further found that it "seemed to be the consensus not only of the treating physicians but also of the several qualified experts who testified in the case, that removal from the respirator would not conform to medical practices, standards and traditions."⁶

At the hearing to consider Mr. Quinlan's application for guardianship, several medical and neurological experts, including Dr. Julius Korein and Dr. Fred Plum, testified that Karen Quinlan was indubitably not brain dead. They cited the report of the *Ad Hoc* Committee of Harvard Medical School as the "ordinary medical standard for determining brain death." Karen's condition did not conform either to its criteria for brain death⁹ or to similar criteris.¹⁰

Karen was unresponsive and had flexion of the upper extremities and extension of her lower extremities, a position associated with partial decerebration. She had sleep-wake cycles. "In the awake cycle she blinks, cries out and does things of that sort but is still totally unaware of anyone or anything around her."⁶

Karen's treating neurologist characterized the result of her electroencephalogram (EEG) as "abnormal but it showed some activity and was consistent with her clinical state."⁶ The case report notes "Electroencephalograms showed cortical activity (predominately low-voltage fast activity [beta] when the patient was awake. When she appeared to be asleep, there was intermittent low-voltage of 3 to 7 Hz (theta), infrequent activity in the alpha range, and occasional slower activity in the delta range,"⁴ activities consistent with a person who is asleep.¹¹ Other neurological tests that were within normal limits included a brain scan, an angiogram, and a lumbar puncture.⁶

Mr. Quinlan visited his daughter daily. In 1985, after Karen had lived some ten years in coma, he stated, "I still have to stop there everyday, even in the snow, just to be sure she is not lacking for anything."⁸

I talk to her, see if there is anything I can do to make her comfortable. Sometimes there is. If she is grimacing, there are little things I can do like moving her feet or combing her hair. It makes me feel good to know there are little things I can do to see her sleeping peacefully when I leave.¹²

Karen's adoptive parents are Catholic. Their pastor and bishop testified on their behalf, claiming the removal of Karen's respirator was consistent with Catholic teaching, citing Pope Pius XII.⁶ The New Jersey Conference of Catholic Bishops filed an *amicus curiae* brief in support of Mr. Quinlan's application.

Noting "the position of that Church as illuminated by the record before us," the Court found:

We have no reason to believe that it would be at all discordant with the whole of Judeo-Christian tradition, considering its central respect and reverence for the sanctity of human life.⁶

In considering Karen's right to privacy, the Court found that Karen would have chosen to forgo the resuscitative treatment, had she been competent to make such a choice, reasoning that the State's interest "weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State interest."⁶ In other words, as stated elsewhere in the Court record, the "Patient's right to privacy was greater than the State's interests in the preservation and sanctity of human life where patient, whose vital processes were maintained by mechanical respirator would never resume cognitive life."⁶

The Court held that:

If a putative decision by Karen to permit this non-cognitive, vegetative existence to terminate by natural forces is regarded as a valuable incident of her right to privacy, as we believe it to be, then it should not be discarded solely on the basis that her condition prevented her conscious exercise of the choice. The only practical way to prevent destruction of the right is to permit the guardian and family of Karen to render their best judgement, subject to the qualifications hereinafter stated, as to whether she would exercise it in these circumstances. If their conclusion is in the affirmative this decision should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them.

Accordingly, the Court determined that "Karen's right of privacy may be asserted in her behalf, by her guardian and family under the particular circumstances presented by this record."⁶

Note the use of "privacy" and "choice" to rationalize further judicial sanction of life-ending decisions by a third-party.

During the second six months following her arrest, Karen began to trigger the ventilator more frequently and she was weaned from it over a period of a month.⁴ She continued to breathe on her own for another ten years. Karen eventually succumbed to overwhelming infection, including pneumonia and meningitis.

Karen Ann Quinlan is dead. *The New England Journal of Medicine* editorializes:

We owe Joseph and Julie Quinlan, Karen's parents, our gratitude for turning their personal calamity into a public benefit by launching the Right-to-Die movement. Without this movement we would not have our present rights to prepare advance directives or living wills that permit us to name a proxy decision-maker to authorize discontinuation of treatment under specified circumstances.¹³

We believe the New Jersey Supreme Court decision in the Karen Ann Quinlan case has fueled the euthanasia movement and jeopardized the lives of countless vulnerable persons, in particular, those living in an unconscious or semiconscious state. But the precise cause of Karen's condition has not been

established. Autopsy findings, preceded by normal CT-scans and normal angiograms, were inconsistent with the widespread and diffuse brain damage expected in the purported "persistent vegetative state" (PVS).

Karen's treating physicians and the experts were wrong when they predicted that she would not survive another year. They were wrong in insisting that she was unaware of herself and her environment, since her father observed her response to touch, stroking, and combing her hair.¹² Physicians can err in regards to prognosis, as well as diagnosis.

The Court record refers to a number of different standards governing medical practice: *pertinent* medical standards, *ordinary* medical standards, *traditional* medical standards, *ethical* standards, *societal* standards, and standards of *civil* and *criminal* law. Most importantly, there was introduction of *accepted medical standards*.⁶ The initial court case (i.e., Karen's father's petition to be appointed her legal guardian for the purpose of making medical treatment decisions) included the contention that Karen was brain dead. Although the Court did not find that Karen was brain dead (following stipulation of the parties), nevertheless it accepted and applied the standard of "accepted medical standards." This is particularly significant inasmuch as the Uniform Determination of Death Act, a statute recommended for adoption by every state by the Uniform Law Commissioners, subsequently required the determination of death to be based on "accepted medical standards."¹⁴ Accepted medical standards are not sufficiently stringent for a matter as important as the determination of death.¹⁵ Many people are unaware that accepted medical standards do not preclude the presence of brain functions when a declaration of brain death is made.¹⁶ For instance, to perform an EEG and to require that the EEG evidence no activity before pronouncing brain death, would be within a standard that could be considered "pertinent, ordinary, and traditional," yet to forgo conducting an EEG prior to declaring brain death falls within "accepted medical standards." Indeed, according to Grigg and colleagues at Loyola University, Chicago, it is accepted to conclude and determine brain death even in the presence of activity recorded by the EEG.¹⁶ Since the Karen Ann Quinlan case, it is not only accepted to remove a ventilator from patients in a so-called persistent vegetative state, but it is also legally and medically accepted to deprive such individuals of food and water.¹⁷ Such patients, receiving neither food nor water, will die, as would each and everyone of us. And they die after experiencing 10 to 14 days of agony, torment which may well be felt by those being starved and dehydrated to death but would be unable to communicate because of not being able to move, cry out, grimace or show other signs of discomfort. A California district attorney described such a death as a "life boat death, a prison camp death, the classic death of dehydration and starvation,"¹⁸ while a Massachusetts judge depicted the tragic sequelae of deliberate starvation and dehydration.¹⁹

Did Karen truly have PVS? The evidence from her father (see page 60) belies this diagnosis. She responded to her father's affectionate gestures. She could have likewise responded to the agony of slow death from meningitis and pneumonia in the last weeks of her life. In a similar way, other persons misdiagnosed as PVS

could die excruciating deaths from the misapplied "kindness" of death from slow dehydration and starvation.

Karen died in 1985. Her brain was fixed in 20% formalin for three years and then examined.⁴ If there was a purpose or reason for this three year delay, it was not mentioned in the *New England Journal of Medicine* article. Nine years transpired from the time the autopsy was performed until the findings were reported in the *New England Journal of Medicine*. It would seem the authors of the article and the editors of the *Journal* would have wanted this article published quickly, especially since the autopsy findings differ from the medical information that had been provided to the Court on which the Court had based its rulings. Why the delays? For whatever reason(s), the delays allowed the idea of withdrawal of treatment, hydration, and nutrition to become acceptable to the public and the courts,^{20, 21, 22, 23} before the flawed evidence provided by this paradigm case was published.

"Contrary to expectation, the most severe damage was not in the cerebral cortex but the thalamus, and the brain stem was relatively intact." It was further concluded that the brain pathology was "consistent with hypoxic ischemic injury and cerebral edema due to the cardiopulmonary arrest that had occurred ten years before death."⁴ There is no mention of the effect of drugs, or anything other than hypoxia-ischemia, as a possible cause of any of her brain pathology.

Autopsy findings included severe cachexia. Karen's brain weighed only 64% of normal.⁴ Cut sections (Figure 2 in reference) were impressive for the degree of cortical atrophy in the parasagittal region from the precentral gyrus of the posterior frontal lobe to the parieto-occipital fissure. It is concluded that the pathologic findings are related to hypoxia and ischemia, but could extreme malnutrition and imbalanced caloric intake by artificially maintained hypercaloric [sic] feedings at one point have caused additional mechanisms for selective vulnerability, such as an extreme form of Wernicke's disease (BI avitaminosis)?²⁴ Brain areas that could be involved in this type of vitamin deficiency, for example, the mammillary bodies²⁴, were not discussed in the paper other than the notation of atrophy. A nutritional role was only mentioned by the authors in relation to degeneration of the spinal cord posterior columns⁴. The modern neuroimaging findings in cases of anorexia nervosa (as in-vivo models of human malnutrition) show reversible brain atrophy (pseudo-atrophy).^{25, 26} While it is reversible and mild, could the same mechanism have caused what was found in the brain of Karen Quinlan who had "severe cachexia"? These questions cannot be answered simply on the basis of the *Journal* article and the Court report. But their very unanswerability would indicate to us that Karen's case was a poor exemplar on which to base the entire present day culture of death.

There was marked atrophy of the thalamus. Linking thalamic atrophy to a permanent state of unconsciousness is thought-provoking. The obvious explanation given for the thalamic atrophy is hypoxic-ischemic insult, but when was the thalamus actually injured? The electroencephalogram recorded low voltage fast patterns, not activity of delta rhythms more characteristic of thalamic lesions.²⁷

The same issue of the *New England Journal of Medicine* that reports the Quinlan autopsy presents a report of The Multi-Society Task Force on PVS. "The vegetative state is a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brain stem automatic functions."²⁸ The principal pathologic finding following acute global hypoxia and ischemia is extensive necrosis of the cortex or an abnormality that isolated the cortex from the other parts of the brain. The EEG usually shows diffuse and generalized abnormalities. Computed tomographic imaging in patients in a persistent vegetative state often reveals diffuse or multifocal cerebral disease involving the gray and the white matter.²⁸

The Court sanctioned the removal of Karen Ann Quinlan's respirator because it found that she was in a persistent vegetative state. Yet, the autopsy, the EEG, CT-scan, and the angiograms did not evidence the customary findings associated with this purported state. Likewise the pathological findings were not consistent with the expected findings of "extensive multifocal or diffuse laminar cortical necrosis."²⁸ Indeed, the autopsy confirmed that the major pathology in the brain of Karen Ann Quinlan was in the thalamus, a small part of the brain.

If the Court had been aware that the major pathology in Karen's brain was known to be in a relatively small part of her brain known as the thalamus, would that have affected its decision? If the Court had known that she didn't require a ventilator for her breathing and would live another ten years breathing on her own, would it have ruled differently? If the Court had foreseen that the cause of Karen's unconsciousness would never be clearly established, would this insight have informed the Court's decision?

And if the Court could have foretold that as a result of its ruling, such consequences as launching the Right-to-Die movement, promoting living wills, legalizing the fatal removal of food and water, and "assisted" suicide might ensue, would the Court have ruled otherwise?

Not much was found wrong with the cerebral cortex. The predominant pathology was in the thalamus when "neocortical death" was expected. In retrospect the Karen Ann Quinlan case was a poor one to base a policy utilizing "partial" brain death, especially involving the neocortex, as a criteria for withdrawal of treatment, food and water.

Our conclusion is that the foundational case for terminating such treatment for patients in coma or persistent vegetative state is flawed because of a failure to properly investigate and diagnose this patient's condition. Its conclusions were unwarranted because the cause of her condition was never clarified. She responded to pain, coughed and gagged. She responded to soothing touches by her father. She had normal CT-scan and normal angiograms which were not consistent with the brain damage espoused by the physicians. Finally, the autopsy findings are not the expected widespread and diffuse damage, rather the major pathology was in the thalamus, a relative small part of the brain. Hasn't the foundational case for the 'Right-to-Die' Movement been built on sand?

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