

## Marking the 40<sup>th</sup> Anniversary of Quinlan's Landmark Contribution to Death & Dying Jurisprudence

In 1976, the N.J. Supreme Court issued a remarkably insightful ruling regarding the legal status of a permanently unconscious patient. In re Quinlan served as a judicial beacon guiding development of death & dying jurisprudence. Its impact is reminiscent of the judicial role played by Brown v. Board of Education in public education.

To appreciate the wondrous nature of Quinlan, recall the setting and background of the case. In 1975, a 22 year-old woman, Karen Ann Quinlan, was lying unconscious in a N.J. hospital following 2 anoxic episodes caused by toxic ingestions. She was sustained by a mechanical respirator and a naso-gastric tube. The diagnosis was PVS (permanent vegetative state) and the prognosis was that the patient would inevitably die within a year without regaining consciousness. Ms. Quinlan's devoted parents reluctantly concluded that their daughter would not want to be maintained in her dismal, hopeless condition. Their priest and spiritual advisor told them that Catholic doctrine would permit withdrawal of "extraordinary" medical intervention such as the respirator. But when the parents asked the attending neurologist, Dr. Morse, to withdraw Karen's respirator, he refused. He contended that professional medical standards precluded that course. The hospital concurred. Facing this resistance, Ms. Quinlan's father turned to the N.J. chancery court seeking formal appointment as his daughter's guardian with explicit authorization to direct withdrawal of the respirator.

A variety of interested parties responded to Mr. Quinlan's chancery petition and they all opposed it. The county prosecutor asserted that pulling the respirator plug would constitute homicide and the state attorney general concurred. The attending physicians and the hospital contended that pulling the plug would violate their professional responsibilities to the patient. And a special guardian ad litem appointed to represent Karen Ann Quinlan insisted that it was in the helpless patient's best interests to have her life prolonged. The lower court denied the father's petition and Mr. Quinlan appealed.

On appeal, the N.J. Supreme Court in 1976 faced the unenviable task of shaping legal policy toward medical conduct likely to precipitate the death of a helpless patient. This was largely uncharted legal territory with no definitive precedents in state or federal courts. Common sense said that it can't be a legal mandate to keep pumping fluids and gases into moribund patients until the last possible breath. Yet a chorus of naysayers proclaimed that pulling the respirator plug on Ms. Quinlan would be unlawful homicide, or a breach of professional medical responsibility to preserve patients' lives, or a violation of a guardian's fiduciary obligation to act in a ward's best interests. And even if some circumstances might warrant removal of life-

preserving medical interventions, hard questions existed about who is entitled to be the decision maker and what test or criteria govern such surrogate decision making.

Despite that cacophony of background voices, a unanimous N.J. Supreme Court, in an opinion by Chief Justice Richard Hughes, rendered a wondrous judgment upholding the prerogative of a conscientious surrogate to dictate removal of life support from a permanently unconscious patient. In re Quinlan, 355 A.2d 647 (N.J. 1976). The opinion had several important insights that have prevailed over time in death and dying jurisprudence. Quinlan elucidated that it is not criminal to manage medical intervention of a fatally stricken patient in a fashion that sometimes removes medical obstacles (such as a respirator) to a natural dying process. The Court pronounced that a competent, fatally stricken patient would clearly be entitled to reject life-sustaining intervention as a matter of self-determination and bodily integrity. Indeed, Chief Justice Hughes declared that a competent patient's prerogative to shape medical intervention was a part of the fundamental liberty protected by the 14<sup>th</sup> amendment to the federal constitution (building on Roe v. Wade from 1973). That insight was later reinforced by the U.S. Supreme Court's language in Cruzan in 1991. The Hughes opinion also observed that a patient's constitutional prerogative to control medical intervention ought not be lost upon the patient's becoming mentally incompetent. Rather, a patient's representative ought to be able to make a "best judgment" about what the patient (if miraculously competent) would want done in the circumstances.

The Quinlan Court was also acutely insightful in shaping the identity of the appropriate patient representative and the criteria by which a surrogate decision maker should be governed. The justices recognized that if judicial intervention were to be imposed in this context, the process of decision making on a patient's behalf would be too cumbersome and protracted. The Court ruled that a natural guardian, such as a devoted parent, could serve as prime locus of authority. (This rejected the lower court position that a parent would be too emotionally overwrought to be entrusted with responsibility). The patient's representative was not expected to act unilaterally. Any withdrawal of life support was supposed to be a joint decision between the patient's surrogate and the attending medical personnel. In fact, consultation with an institutional ethics committee might also be desirable. At the same time, the Court rejected any notion that the "professional judgment" of any particular attending physician would be determinative in the handling of a permanently unconscious patient. While Dr. Morse felt that removal of life support would violate his professional responsibilities, many other physicians had a divergent view of professional responsibility in the circumstances. They would be willing to cooperate in removal of life support from a patient no longer drawing meaningful benefit from mechanical intervention.

Quinlan was no less astute in shaping the criteria to be employed by Mr. Quinlan in shaping his daughter's medical fate. The invocation of "best judgment" about how his daughter

would have opted was a prescient anticipation of the substituted judgment standard widely used today as the lodestar in surrogate decision making. Further, the Court understood that the dismal quality of life entailed in permanent unconsciousness provided a key index for assessing how Ms. Quinlan would wish to be treated. If Mr. Quinlan determined that his daughter would abhor a non-sapient state without any cognitive life, this determination would be understandable and supportable because “an overwhelming majority” of people would exercise the same choice for themselves. The Court grasped that most people would deem this grievously deteriorated mental state to be an intolerably undignified status in which they would not wish to be medically sustained.

Quinlan ostensibly furnished a sage path for shaping end-of-life care in the wake of precipitous, permanent cognitive dysfunction. My naïve assumption at the time was that Quinlan’s guidance would definitively resolve the bulk of such cases. I figured that most people would define for themselves (via advance instructions) the level of post-competence mental dysfunction which they would deem intolerably undignified. And I projected that shared notions of indignity would emerge abjuring continued life support in cases not only of permanent unconsciousness, but also of extreme dementia precluding meaningful interaction with the patient’s environment. I anticipated an emerging consensus that for previously competent persons such permanent cognitive decline would constitute a degrading specter soiling their life image to be left with survivors. Inability to recognize and interact with surrounding people – as in advanced Alzheimer’s – would widely be deemed intolerably degrading by issuers of advance instructions.

I also figured that conscientious surrogates would then commonly use such advance instructions to dictate withholding of medical intervention preserving an unwanted, cognitively debilitated status. And that medical professionals would readily cooperate in implementation of patients’ determination to avoid a prolonged immersion in an uncomprehending, non-communicative status deemed in advance to be intolerably degrading.

My vision of Quinlan’s application has not materialized. While Quinlan indeed set a salutary framework for allowing people to shape their post-competence medical fate, I failed to account for a number of complicating factors in end-of-life practice. Many people fail to issue advance instructions. Even when advance instructions are present, they are sometimes imprecise and unhelpful. Even when a patient’s wishes are apparent, patient representatives sometimes fail to implement those previously articulated wishes. A friend or relative acting as the patient’s surrogate may be deterred from withdrawing life support by irrational hope for recovery, by guilt in bringing about a loved one’s demise, or by medical professionals’ opposition to the patient’s desired course. Some medical professionals (and some health care institutions) cling to a vitalist vision of medical responsibility to preserve even severely demented patients who did not want to

be sustained in this status. Such medical opposition poses a barrier to a conscientious decision maker's effort to implement advance instructions.

Quinlan still deserves to be celebrated for its prescience. It upheld the central role of conscientious family and friends in shaping the fate of now-incompetent medical patients. It identified the critical object of following the course that the patient would want in the circumstances at hand. And it understood that shared notions of intolerably degrading cognitive decline could be an integral factor in shaping people's preferences for end-of-life care. Unfortunately, 40 years have not sufficed to fully and uniformly integrate the lessons of Quinlan into American medical practice. Just as Brown v. Board of Education, for all its wisdom, could not judicially create integrated schools, Quinlan has not universally relieved moribund patients from being mired in an unwanted, cognitively unaware limbo.