

The Infamous *Farrell* Footnote: Public Policy as the Smile of the Cheshire Cat

JOSEPH C. D'ORONZIO

It is early in 1998. A Network-Up-To-The-Minute-News-Every-Hour voice exclaims with that excited and slightly incredulous energy: "If you're in New Jersey and you are terminally ill and you want to refuse treatment that might save your life," the anchorman cries out, "you are considered incompetent until you can convince THREE physicians that you're not! More on that after the weather!"

Was this just another incendiary sound bite, headline news banner attacking the airwaves? Getting it wrong? Overstating some small technicality for the sake of getting attention? No, to all of the above: the most incendiary aspect of the blurb was that it was accurate. And it did get attention.

For the better part of 1998, the New Jersey bioethics community grappled with this anomaly. The requirement that three physicians must confirm a patient's "competency" before that patient may refuse life-sustaining therapy has broad application. It applied equally to withhold/withdraw requests, to no intubation orders, to withholding consent for, say, lifesaving surgery, and to writing DNR orders. It applied equally to every setting over the continuum of care. It overrides well-established physician-patient relationships and long-standing communication. In some cases, it overrides the advance directive process. In short, the three-physician rule implies that there is no presumption of decisional capacity for New Jersey patients whenever a patient refuses treatments that are thought to be life sustaining.

How, exactly, did physicians in New Jersey follow this rule? The fact is that they did not follow it. Because it ran counter to accepted professional standards and practice, it was widely ignored in the clinical setting. Nevertheless, the tension between professional standards and this legal requirement generated a compelling public-policy debate. The debate was particularly energized by the fact that this issue is neither esoteric nor arcane. It was a fundamental patient right and physician responsibility that was turned on its head. The presumption of the patient's decisional capacity is baseline bioethics. It has been long resolved in law and professional practice. Why was it challenged? And on what grounds of law, public policy, and/or professional standards?

Before turning to the specific case that was addressed in this debate, it is essential to remark on the public-policy process that led to it and the continuing problems that issue from it. Public policy is often like the smile of the Cheshire Cat, lingering as a leering presence long after the specifics of the case itself have receded from view and memory. Even as the finer points of this singular episode in medical ethics get resolved, it is by no means certain that a similar debate might not erupt in the future. Thus, the overarching issues are public-policy issues.

Should basic bioethics standards find expression in public policy? Or should they be left alone to the less well-defined realm of professional ethics and its practiced reliance on case-specific consensus? What is the appropriate form for bioethical policy—legislative, judicial, administrative, professional society, the fourth estate? Or, perhaps more to the point in our pluralistic and multicameral political system, might every form be included? Finally, what processes might be put in place to reference all the stakeholders in the complex web of accountability that marks healthcare?

Much to the credit of the New Jersey bioethics and medical communities, the heat of the debate did not vaporize these larger issues. What originates as a debate over fine points of law and bioethics ultimately became a conversation about appropriate ways to align policy with professional practice. The *Farrell* case was the occasion for promulgating public policy radically at variance with standard professional practice. The policy conversation that ensued was the setting for a remarkable nonjudicial review, and effective reversal, of a decade-old case law through reassertion of a fundamental concept of bioethics. In the end, this historic confrontation of regulatory law and bioethics generated a unique institution in the repertoire of the New Jersey Board of Medical Examiners.

The Background

New Jersey has a well-deserved reputation for having an activist court enabled by a passive legislature in the area of bioethics and the law. It is the home state of landmark court decisions, but it's a backwater of legislative initiatives. New Jersey was a hold-out state for legislation supporting advance directives and neurological criteria for death. It did not address these issues on the legislative level until fully 15 years after its Supreme Court broke ground for patient/family self-determination and physician-based neurological prognosis in *In re Quinlan* (1976) and, later, *In re Conroy* (1985). Although these court decisions boldly supported patients and families and suggested innovations such as the role of an "ethics committee," the legislative forays were cautious and hesitant, permitting exceptions and caveats that are rare or nonexistent in other states.¹

New Jersey also is noteworthy for having had a Bioethics Commission devoted to public-policy issues in bioethics, one of only two such state bodies in the United States. This commission was brought into existence by the legislature in 1986. It developed reports in several areas, recommending some successful legislation and, under both financial and political pressures, was defunded in 1993.² Among several important informal roles of the New Jersey Bioethics Commission was its identification (one is tempted to say, creation) and solidification of the bioethics community in the state. Through its various task forces, hearings, reports, and publications, the Commission placed itself in the communicative center of a cadre of individuals from a variety of disciplines and philosophical orientations. It succeeded in nurturing an informed, articulate, confident, and perennially interested bioethics community.

The New Jersey Bioethics Commission was denied the allocation of funds by the legislature but has never been formally disbanded, leaving behind a "shadow commission" of bioethics notables whose activities have percolated through most of the state's 100 hospital bioethics committees, professional societies, and college and university programs. This community generates a fairly high level

of consciousness about bioethical issues and maintains vigilance over public policy and professional standards.

About ten years after *Quinlan*, the New Jersey Supreme Court considered a triptych of withdrawal of life-sustaining-treatment cases—*Jobes*, *Peters*, and *Farrell* (1987). Each of these decisions supported the patient and family in their determination of treatment alternatives, including the determination of a refusal to maintain treatments that support life. This is, after all, the court of *Quinlan* and of *Conroy* and although there were fine points in all these decisions that created some suspense at the time, the direction of these decisions was not surprising. Patients of various ages and in diverse circumstances together with their families and in close communication with their physicians were again empowered to refuse and reject life-sustaining treatment.

The Court Opinion: *In re Farrell*

In the case of interest, that of Kathleen Farrell, the court considered this right for a 37-year-old homebound patient with amyotropic lateral sclerosis (ALS) who wished to have her respirator disconnected. In their opinion, the court set up certain requirements that would permit this expression of patient self-determination to occur in the home-care setting. These were so explicit that, for a period of time, the process of meeting these requirements were sardonically referred to as “farrellizing” to distinguish it from “consenting” [a patient]. In truth, it was merely a rare articulation of a rigorous informed consent process which stressed documentation that the patient was fully informed as to prognosis, available medical alternatives, risks involved, and the likely outcome if specific medical treatments were discontinued. Special attention was directed to the issue of possible undue influence or coercion by other parties.

In all this, the court focused on the fact that this was a homebound individual. It asserted that there is no difference in the rights of a patient cared for at home. It also dismissed the idea that a patient would be more vulnerable at home, contended that the opposite may be true, considering the attendance of caring family in the home setting. In the key passage of the decision, however, it does point out that some elements of a careful informed consent process

... are more easily resolved when the patient is in a hospital, nursing home or other institution, because in those settings the patient is observed by more people. To protect the patient who is at home, we require that two non-attending physicians examine the patient to confirm that he or she is competent and is fully informed about his or her prognosis, the medical alternatives available, the risks involved, and the likely outcome if medical treatment is disconnected. (*In re Farrell* 108 New Jersey 356)

The heart of the informed consent process, clearly, is the capacity of the patient to understand and decide. It is worth noting that the court clearly felt that in the context of a hospital or nursing home there would be more surveillance or exposure to other healthcare professionals—casual or even formal—that would not make this requirement necessary. The opinion goes on to further justify this procedural requirement as one which would “... forestall hasty medical decisions made while a patient is in an emotionally disturbed state

because of a sudden illness or major catastrophe." Thus, a more stringent procedural requirement was put on the physician for determination of decisional capacity of the homebound patient as part of the informed consent process.

It is with respect to this "two nonattending physicians" procedure outlined in the *Farrell* opinion that the following footnote is inserted and which soon attained a life of its own.

The procedure we hereby establish for determining the competency of a patient at home who has decided to forego life-sustaining treatment is likewise applicable to patients in hospitals and nursing homes. (*In re Farrell* 108 New Jersey 356, footnote 8)

From Case Law to Medical Board Policy

This footnote was the source of controversy in the New Jersey Board of Medical Examiners guideline, "Policy Statement on the Withholding or Withdrawing of Life Sustaining Medical Treatment." The Policy Statement was not particularly new in January 1998. It had been published three years before, in 1995, as an attempt to integrate the New Jersey advance-directive legislation (1991) with existing case law and existing Medical Board standards.

The status and function of a Board of Medical Examiners "policy statement" is of interest and is not well understood. It is not law, it does not constitute "rule making," and it is not a form of legal regulation. Rather, it is intended "to provide practitioners with a comprehensive resource document," summarize existing positive law, case law, and regulation as a basis for providing guidance and direction.³ As a publication of the Board of Medical Examiners, it carries the heavy weight of licensing authority, and one ignores a policy statement at some obvious peril. Such policy statements, however, cannot be said to be "enforced" except through some complaint or systematic scrutiny. In this case, the particular procedure outlined in the statement has been widely ignored by that small proportion of the state's physicians to whose activities it may apply. This accounts, in part, for the fact that the controversy had not erupted sooner.

Nevertheless, the "policy statement" is clearly at variance with professional standards of practice and ethical decision making as we know it. It was on that basis of principle, rather than, for example, a legal suit or Board complaint that the policy was challenged, mainly by the Medical Society of New Jersey on advice from its ethics committee.⁴ Since it became controversial, a good deal of energy has been devoted to assigning responsibility and attempting to understand how we got to that point. There is no denying that the requirement is in the case law and that it is unambiguous. The Board of Medical Examiners was earnest, perhaps even zealous, in its reading of the requirement and the promulgation of the policy statement. But claims that the policy statement is inaccurate or inappropriate as a guideline based on New Jersey law are not well founded. It is the court's opinion itself that, although not exactly ambiguous, is certainly inconsistent.

Speculation on the reasoning of the court is a hazardous undertaking. We must assume that the court was cognizant that having the requirement revert back to the inpatient setting was to have an impact on all patients. With that understanding we might try to identify motives for the requirement that are

consistent with other opinions of the New Jersey Supreme Court. This is not as hard to do as may be thought at first glance.

The court may have wished to keep every possible case out of the judicial and guardianship process by setting a new gold standard for consent in every setting. This was a leading trend of this court and, perhaps, its most marked legacy. The “two nonattending physicians” approach, however, is both cumbersome and at odds with professional standards. It may actually reduce patient self-determination and diminish the physician–patient relationship, both of which are also hallmarks of this court. Nevertheless, having two extra physicians affirm capacity was preferred by this court as a support of self-determination, especially when compared to bolstering patient rights through guardianship or other judicial review.

Perhaps the “two more opinions” injunction in *Farrell* can be explained as an echo of the *Quinlan* requirement for two nonattending physicians to confirm a prognosis of persistent vegetative state. The medical judgment mandated in *Quinlan* to reassure that a patient is unlikely to return to a “cognitive and sapient state” may have suggested a parallel competency requirement.⁵ Although they are quite different levels of judgment, the consequence of the judgment—removal of life support—may have suggested a parallel in the judicial reasoning.

It has been suggested, finally, from a highly focused medical perspective, that the case of Kathleen Farrell was a very narrow clinical circumstance. She was a person who was ventilator dependent and extremely compromised in communication and ambulation. Her husband alone was able to understand her slurred speech, and then not always. She used a spelling board as an aid, but her movements were so restricted that the board often needed to be moved under her hand to enable her to indicate the desired letter. This clinical circumstance defined her as “homebound.” Following this reasoning, we might conclude that this was the clinical circumstance that characterizes “cases such as this” whether they appear in hospitals, nursing homes, or in the home-care setting.⁶

These speculations are suggestive of the direction of the court’s deliberative processes, but they are not satisfying. For we are left, finally, with the flaw of inconsistency. The overarching problem that inspired the controversy is an essential discrepancy that one hopes, in vain, is merely literary or typographical. Conceptually, it may have been the force of the argument for broader scrutiny of the consent process, generally, that moved the court to insert an afterthought in the footnote. That it was not in the text of the decision supports this speculation. If so, it helps to explain the contextual inconsistency that might have been the result of not reintegrating the larger concept into the text of the opinion. Or, more likely, not thinking through the reformulation and implications of this “gold standard” consent process.

These are unsettled historical hypotheses. A well-meaning court attempt to keep patient care decisions out of the courts created a burden not worth the benefit. For the state’s bioethics and health law community, it has been an uncomfortable situation. A realistic and pragmatic professional standards approach has generally dominated. Although it is difficult to advise physicians to ignore the policy statement, doing so has had no impact on standard professional conduct. The “only” problem that remained was one of principle and conscience.

Is the Cheshire Cat’s smile of this policy going to sneer down on us long after its authors and its critics have lost both their memories and that of the Farrell case? How can we live and function with this problematic statement lingering

“on the books”? We had engaged the issue in many informal arenas, but it was not until the ethics committee of the Medical Society of New Jersey joined with the New Jersey Ombudsman for the Elderly, the local Veterans Administration, and New Jersey Health Decisions to pursue relief that the Board’s policy statement resurfaced early in 1998.

The Policy Dilemmas

Responding to petitions from these groups that cited the obvious practical concerns and the deviation from well-established and broadly accepted professional standards, the Board of Medical Examiners agreed at first to take the matter under advisement and in the interim to

exercise prosecutorial discretion . . . by not pursu[ing] disciplinary action against a licensee who might fail to get the two physician competency evaluation where there is no clinical indication of incompetence or undue coercion and where there is fully informed consent.⁷

In the meanwhile, the first order of the day was to explore the options for resolution. The Board requested opinions from a full range of medical societies, academies, and other professional and bioethical associations. The central dilemma was that the Board policy statement followed a court opinion that was, in itself as we have described, at variance with the professional standards. Even if the New Jersey Supreme Court opinion is misguided, it is, after all, still current.

These circumstances presented some overwhelming constitutional issues and dilemmas. Can the New Jersey Supreme Court opinion be contradicted by a new Medical Board policy? Need the issue be adjudicated to be resolved? Would state constitutional conflicts be engendered by the Board revising their policy statement in a way that is inconsistent with the case law? May the Supreme Court be petitioned for some kind of review or declaratory judgment?

Additionally, a range of uncomfortable tactical approaches agitated communication. Was it necessary to mount a challenge to the policy in an adversarial confrontation between the Medical Board and the petitioners? Should a new “case” emerge designed to challenge the current precedent? If so, from which quarter might such a case be initiated? For example, a physician as plaintiff to license revocation, or a patient as plaintiff to a physician who concluded decisional capacity without two other consultants? Finally, what role might regulatory or legislative initiatives have to obtain relief?

Although uncomfortable as critic of its own policy, the Board of Medical Examiners was best positioned to pursue these alternatives. A state medical society must be clearly reluctant to make special claim to unilateral activity, either in opposition to the policy statement or to the substance of a case law ostensibly intended to protect a vulnerable patient from just such unilateral action of physicians. Although each of the above alternatives might be pursued jointly and cooperatively, in the last analysis, it is the Medical Board’s policy. In this, as in so many policy positions with ethical significance, both the clarity of intention and the responsiveness of the agent are important. A new policy statement that attempts to recapture the spirit of the opinion in *Farrell*, leaving the inconsistent footnote to the letter-of-the-law compulsives, was agreed to be a reasonable solution.

Reconstructing Intention from Earnestness

In March of 1998, following a petition by the New Jersey Board of Medical Examiners, the New Jersey Supreme Court bestowed its blessings on the Board to attempt to amend the 1995 policy statement. The way was clear to the least contentious of alternative resolution of the problem. The Board held an “informal” public hearing in early May to receive formal comment and proposals for changes in the policy statement. Given the apparent clarity of the issue, it is a wonder that there was so much more to be said.

The New Jersey bioethics community, tempered by more than two decades of precedent-making court decisions and organized briefly by a state bioethics commission, is a formidable chorus. Out in full force, its sophistication overpowered the *Farrell* decision, the Board of Medical Examiners policy, and, of course, its own past accomplishments, particularly the advance-directive initiatives.⁸ The Board heard that no other state has such a requirement (from the New Jersey Assembly Health Committee chair); that no New Jersey hospital is following the current policy (from the New Jersey Hospital Association Physician Executives Group Chair); and, (from the State Health Commissioner, among others) that the state has already passed legislation, in its Advance Directives for Health Care Act of 1991, that contains decisional-capacity standards that might well supersede *Farrell*.

The challenge before the Board was, more clearly than ever, not whether a change in its policy was possible, but rather what the new policy would say. In the deliberative process following on these hearings, the issue of intention was forcefully clarified. First, the existing policy made a presumption of incompetence that must be reversed to reestablish the primacy of the patient’s right to decide. Second, the language of “decisional capacity” must replace the language of “competency.” This will reassert the ethics of individualized autonomy based on case-specific information and decision-specific capacities of the patient.

Once these intentions are clear, the current professional standards were, indeed, explicated following the broad direction of the three 1987 decisions, including *Farrell*, without its onerous restrictions and caveats. That is, in the present wording, the patient “should be presumed to have decision-making capacity, if he or she has the ability . . . to reach an informed decision.” The criteria for “informed consent” is spelled out as it previously was, but all of this is to be determined by the single attending physician. When the primary physician determines that the patient may not be decisional and needs to consult, the physician should seek appropriate consultation. The new policy statement leaves the nature, scope, and number of consultants open.

Pulling the Thread: A Bioethics Committee for the Board

This story has a happy enough ending. As the policy debate progressed over the year, it seemed very much like an exercise of “getting back to basics.” How much more basic can one get than informed consent, the presumption of decisional capacity, the primacy of the physician–patient relationship, and the integrity of the health professions? Although there was certainly a contentiousness about some issues and even a little acrimony, oppositional lines soon blurred

and melded into a common purpose. Conversations among the participants moved from self-righteous assertiveness to mutually comfortable and confident camaraderie. The whole episode was eventually marked by this spirit of cooperation: from the encouragement of the New Jersey Supreme Court to pursue the unusual nonjudicial procedure through to the final responsiveness by the Board of Medical Examiners to ethical, rather than legal, reasoning and (perhaps ironically) to professional standards.

But after the May, 1998, hearings, a rumbling undercurrent could be discerned that had a different quality. Although the focus of the hearing was on the specifics of the *Farrell* requirements, several of the commentaries added to their agenda another onerous item in the same policy statement. Within another section on "No Code Orders," there was a requirement that the Do Not Resuscitate Order "should be countersigned by either the patient or by an independent qualified witness not involved in the treatment of the patient." Withholding cardiopulmonary resuscitation was correctly identified as one class of life-sustaining medical interventions and its connection with the *Farrell* opinion needed to be clarified.

At first, the Board's response merely extended changes of wording from "competency" to "decisional capacity" in the DNR section and maintained the countersignature requirement as peripheral to the issue at hand. But the comments of the bioethics community became increasingly pointed. Having attained the reversal of the *Farrell* three-physician requirement, deleting the DNR countersignature was next. Again the public commentary, again in response to public notice in the *New Jersey Register*, again the objections that these overly legalistic and impractical requirements went counter to the professional standards and tended to eclipse the basic ethical requirements of the physician-patient relationship.

The level of sophistication and deeper understanding of this reaction must have been overwhelming for the Board. For as the basic commentary on the inappropriateness of the countersignature was asserted, additional impatient commentary on smaller, but finer points of law and ethics were asserted. Further wording changes were suggested, and most taken. Nuance of expression in commentary were excepted, and suggestions for rewording were put forward. The Board of Medical Examiners was clearly in the bioethics business and needed help.

But is this not also an ongoing feature of the bioethics endeavor? The policy process of consensus building represents a familiar negotiation among several stakeholders. The third notice of the Board of Medical Examiners policy revision now responded to these objections and eliminated the countersignature requirement for the DNR order. That much was a nearly forgone conclusion. And tucked into this (presumed) final notice of adopted changes in policy statement, there is another notice.

The Board of Medical Examiners of New Jersey has established a Bioethics Committee. Its membership will draw on the New Jersey bioethics community, among others. Its mandate is to receive any further comments on this policy or on any other Board assertions that may have bioethical significance. We believe this to be the only Medical Board in the United States to have such a committee, smiling back benignly, Cheshire-like from a depleted policy debate and forward to more directly engage its community in future policy statements.⁹

Notes

1. The most notable of these are the religious exception from the neurological criteria in the New Jersey Brain Death law and the explicit legal recognition of the nondecisional patient's right to nullify an advance directive written and witnessed while decisional.
2. The New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care successfully addressed legislative initiatives for Brain Death and Advance Directives. Its reports addressed both of these topics and also Reproductive Technology and the Law and drafts on such topics as ethics committees and deciding for the incompetent. [See New Jersey Bioethics Commission, *Problems and Approaches in Health Care Decisionmaking* (State of New Jersey, Trenton, New Jersey: 1990).]
3. *New Jersey Register*, 1998 Jul 20;30:2788.
4. Hardly an accident that the two chairmen of the Medical Society of New Jersey (MSNJ) Committee during this process were former members of the New Jersey Bioethics Commission, and that the legal advisor of the MSNJ Bioethics Committee was once cochair of the State Commission.
5. This requirement in the *Quinlan* decision generated a process of confirming prognosis that was soon to find itself in Department of Health policy guidelines as a "Prognosis Committee" in 1978 and which itself soon generated the "ethics committee" movement in the state, to address all matter of patient decision quandaries.
6. A more extensive version of this perspective is at the center of an article on the *Farrell* footnote by Michael Nevins in *New Jersey Medicine* 1999;Feb:41-43. Dr. Nevins, a former Bioethics Commissioner, was among those who initially stimulated the reconsideration of the Medical Board policy in 1998.
7. New Jersey Board of Medical Examiners Minutes, Feb. 11, 1998.
8. Of the 25 individuals who provided testimony on May 6, 1998, six were former New Jersey Bioethics Commissioners and six held public or professional positions that were represented on the New Jersey Bioethics Commission. National organizations sent an additional four speakers, and the remainder came from various situations. One each were identified as citizen, private practitioner, and philosopher. Health Commissioner Len Fishman, who previously had a well-established role in the state bioethics community as a leading member of the New Jersey Bioethics Commission, also gave testimony.
9. On January 7, 1999, A 2761 was introduced in the New Jersey Assembly. The bill would reconstitute the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care and would appropriate \$99,000 to cover the costs. It was defeated.