

Editor's Introduction: Family Privacy and Persistent Vegetative State

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In this issue, *Law, Medicine & Health Care* is publishing a mini-symposium on the *Linares case*. Six-month old Samuel Linares aspirated a deflated balloon at a birthday party on August 2, 1988. The upper airway obstruction resulted in rapid respiratory failure and cardiac arrest. Rudolfo, his father, rushed Sammy to a neighborhood fire station where the balloon was removed from the child's throat with a forceps. Sammy was taken to MacNeal Hospital where he had no pulse. Cardiopulmonary resuscitation was provided until a normal cardiac rhythm was established. Sammy had no vital signs for at least 20 minutes. Sammy was then transferred to Rush-Presbyterian-St. Lukes Medical Center, and connected to a ventilator.

A pediatric neurologist later diagnosed Sammy as being in a Persistent Vegetative State (PVS). Electroencephalograms (EEGs) showed minimal brain activity; he had fixed and dilated pupils, no deep tendon reflexes, and no reaction to painful stimuli. John Lantos, Steven Miles, and Christine Cassel in their article in this issue explain that PVS describes patients with "irreversible brain damage who pass from deep coma into a state without awareness or cognition but with seeming wakefulness and reflex responsiveness.... They have no evidence of purposeful awareness or response to their surroundings and do not feel pain."

Rudolfo Linares expressed a clear desire to remove his son from the ventilator. The hospital did not do so based on the view of Max Brown, the hospital counsel, that state law could impose criminal and civil liability on the hospital and physician. Sammy was neither brain dead nor terminally ill. Attempts to wean Sammy from the respirator were unsuccessful because he lacked sufficiently effective respiration to tolerate substantial reduction in the level of his ventilatory support. Max Brown's reading of Illinois law suggested that it was an offense to cause the death of a person, and no immunity is given to physicians who withdraw life support in good faith.

Max Brown opined that the only legally permissible

option was for the family to seek a court order. He accepts the criticism that the hospital should have provided the family with resources to seek such an order.

Mr. Linares visited his son frequently. During a visit on the morning of New Year's Eve, he took Sammy off the ventilator. However, Mr. Linares was restrained by security guards, and Sammy was reconnected to the ventilator.

The hospital decided in April to transfer Sammy to an extended care facility because, as an acute hospital, it could not provide long term nursing care. The hospital states that the family approved the decision, but the family was first notified of the specific transfer date on a message left on a telephone answering machine.

Mr. Linares entered the hospital on April 25th with a handgun. He held hospital staff at gunpoint. He disconnected the respirator, holding his child in his arms nearly an hour until he was "cold" and had died.

The *Linares* symposium in this *LMHC* issue is distinctive by any measure. We are publishing the only detailed first-hand account of the facts and reasoning of the principal health care and legal professionals who made decisions on behalf of the hospital. Gilbert Goldman, MD, Karen Stratton, CCRN, and Max Brown, JD, provide a careful and sensitive account of the hospital's difficult decision to follow a course which they believed the law required, but with which they did not necessarily agree professionally or ethically.

LMHC is also adopting a case method to examine the heated issue of whose choice the manner and timing of withdrawing life sustaining treatment should be—the health care professionals, the family, or the courts. Our purpose is not to hold an inquiry into actions taken by the hospital, physicians, or the family in the *Linares case*. Rather, it is to bring together attorneys, health care professionals, and bioethicists in a rich interdisciplinary discussion of the agonizing choices that occur daily in health care settings.

One is driven by the startling facts in the Linares case to try to attribute blame. The problem, I suggest, is with the law, and not with the health care professionals, in-house counsel, or parents in this case.

The main criticism of the hospital really ought to have been directed against the legal system. Health care providers, it is argued, don't need an explicit law to authorize a broad spectrum of medical or nursing decisions. If withdrawal of respiration devices, or even nutrition and hydration, is just another clinical decision, then no special legal justification should be necessary.

But this argument ignores the hospital's point that there are specific statutes on their face which lay down criminal and civil penalties for causing death. The critics argue that health care professionals could have disconnected the respirator and taken the legal consequences. Indeed, I am unaware of any occasion in which there has been civil or criminal liability in a case such as this—i.e. where life support in a patient in PVS is withdrawn with the family's consent. Most people, however, do not have the courage to disobey legal requirements to act in accordance with their moral beliefs.

Nor is the matter of civil and criminal sanctions as trivial as some suggest. There still exists a considerable body of opinion that legal proscriptions against causing death may be applicable in a case like *Linares*, and that health care professionals are not exempt. The District Attorney in Illinois was quite prepared to regard the emotional act of Rudolfo Linares as manslaughter. Would he have taken a different view if faced with a planned, deliberative decision by the hospital to withdraw life support without prior judicial approval? In addition, many still believe that the "right to life" is a legal-social-political decision to be made by the courts rather than by health care professionals and families.

Still, the hospital could have done what most other health care providers have done and continue to do. They take quiet, private decisions to allow death behind closed doors. Health care providers and families take these decisions quite privately because they are confident of the professional and personal ethics involved, but distinctly uncomfortable with the lawfulness or public response. We may be content to allow this private medical and familial decision-making to continue. But such quiet, private decisions can be dangerous, as we discovered in the 1970s, when some physicians' judgments to withhold treatment from Down Syndrome infants were seriously flawed. If decisions to abate life sustaining treatment are taken privately, then some may be made with improper motives, some with insufficient evidence of the patient's prior wishes, and some in cases where the patient may have the potential for meaningful human life. To invite physicians and families to make private decisions is to give them a power we might come to regret. The law, then, needs to set clear parameters around medical and

familial decisions, so that there is public accountability. No one is well served by secret decisions without any openly debated criteria or process.

The problem, then, is that the law in many states still is unclear, leaving open reasonable doubt about whether prior judicial approval is required and in which cases. The Supreme Court has an opportunity to set a much needed national standard in *Cruzan v. Director of Missouri Department of Health*, and not simply to leave the decision to the inconsistencies and vagaries of state law. The Supreme Court should follow the wide consensus of professional and ethical thinking by making clear, minimally, that there is no liability and no need for prior judicial approval in the following case: the patient is diagnosed to be in PVS through a reliable process; the family and health care professionals agree that the medical intervention should be discontinued; and the family is properly motivated. Some review process, perhaps by a hospital ethics committee, may also be appropriate. It should not matter whether the abatement of treatment involves a ventilator as in *Linares*, or hydration and nutrition as in *Cruzan*.

The outcome would be supported by a careful balancing of individual and state interests in treatment abatement cases. The state interest asserted in the life of a person in PVS is purely theoretical. The state's duty to preserve "life" has become a magical concept, often driven by blind ideology rather than by any thoughtful appreciation of the unique characteristics of human life. When an individual has no meaningful interaction with her environment, no recognition of familiar persons or objects, nor any human feelings or experience of any kind, the state's interest in life is a mere abstraction.

To assert an interest in the outcome of a decision to abate life sustaining treatment there must be some demonstrable burden. All of that burden is borne by the family who suffer from the refusal of the law to allow a decision to dignify a natural death process. Whether the burden of continued life is measured by emotional suffering, by economic cost, or by any other standard, it is not society, the medical profession or the state that has to pay the cost. The family must live with the consequences.

The right of a person in PVS to be allowed to die is now well grounded in bioethical thinking. What greater purpose could a constitutional right to privacy achieve than to reject unwarranted state intrusion into such an intimate moment as death? The essence of the right to privacy is that the decision is deeply personal and critically important in the ordering of a patient's life. It is a decision which uniquely involves the individual, and where the outcome matters little to third parties—no one else is harmed by the decision, affected by it, or is properly interested. A family's decision to abate treatment of a loved one in PVS is supremely a private decision.

There are those who suggest that the "right to die" is a legal matter, not medical or familial. Accordingly, decisions to abate treatment should be made only by order or declaration of a court. It is argued that the courts should accede to the family's wish to terminate a person's biological existence only when there is clear and convincing evidence of a carefully deliberated choice by the patient. Lawyers frequently believe that the involvement of a court is necessary to preserve human rights. But to thrust a lengthy judicial process on so private a decision in so clear a case merely serves as an obstacle to the justice and decency which the dying and their families deserve. Prior judicial review has tremendous costs. Poorer people may lack access to the courts; the inordinate time it takes to decide cases only prolongs the human suffering of the family; and the public and adversarial forum defeats the very purpose of a constitutional right to privacy.

The constitutional right to privacy is traditionally founded upon the patient's undoubted right to decide for herself to abate life sustaining treatment. Incompetent patients are entitled to the same privacy rights as those who are competent. This "autonomy" rationale for the right to privacy places emphasis on a person's freedom to decide for herself. But I am reluctantly coming to see this rationale, by itself, to be insufficient to protect the privacy of the family unit. Indeed, the need for evidence of an incompetent person's prior choice has become more a barrier to the right to privacy than a support for it. As hard as such advocacy organizations as Society for the Right to Die may try, most people do not leave clear wishes about their preferences for treatment. Even if they did, many directives would not address the precise set of issues that a dying patient may face; nor does an incompetent patient necessarily have the same values and perspective as when she was competent. The fact is that the claim to know what an incompetent person would want to decide about her treatment is a mere legal fiction. Even the family, who knows the patient best, cannot actually know what she would have chosen.

So long as the law relies on this legal fiction, it may be difficult to defend a right of privacy in cases involving incompetent, particularly never competent, patients. The patient's lack of awareness of her plight also makes it difficult to assert a right of privacy and dignity for her sake alone. The right to privacy that is actually being asserted

is a right belonging to the family unit which includes the patient. It is a right to be let alone in arriving at a decision fundamental to the family's perception of a dignified death and a decent mourning process. No entity other than the family has a real stake in that decision. I would not allow insufficiency of evidence on the patient's prior wishes to become a barrier to the decision of a family to allow a patient in PVS to die. Because the state interest is so insignificant and because the familial interest is so powerful, I would place the burden of proof on the state to demonstrate that the patient would have wanted to live, in defiance of the family's wishes.

The American Society of Law & Medicine has undertaken a sustained examination of treatment abatement issues at the end of life. We began with our last issue of *LMHC* devoted to "Life and Death Choices"; and we continue in this issue with the Linares symposium. The next issue of *LMHC* will be devoted to London 1989: the Second International Conference on Health Law and Ethics. That issue will contain international perspectives on a variety of medico-legal topics, including "Life's End."

Finally, ASLM will be joining with Concern for Dying and the George Washington University Center for Aging Studies and Services to put on the major event examining the Supreme Court's forthcoming decision in *Cruzan*. The conference will be held on September 14-15, 1990, at the Hyatt Regency Crystal City near the National Airport (Washington, D.C.). Alex Capron and Joanne Lynn will co-chair that conference, which will involve a wide spectrum of leading medical, nursing, and advocacy organizations from across the nation as cooperating sponsors.

My hope is that these events will provoke reader response through letters to the editor and other commentaries so that we can continue the clinical, ethical and legal debate in the post *Cruzan* era.

This is a rich issue of *LMHC*. In addition to the Linares symposium, we present articles on the right to privacy and abortion following *Webster v. Reproductive Health Services* by Lynn Wardle, Charles Baron, Rebecca Cook and Bernard Dickens. We also present an exciting exchange of views between Mark Hall and Haavi Morreim who examine the malpractice standard under health care cost containment.