

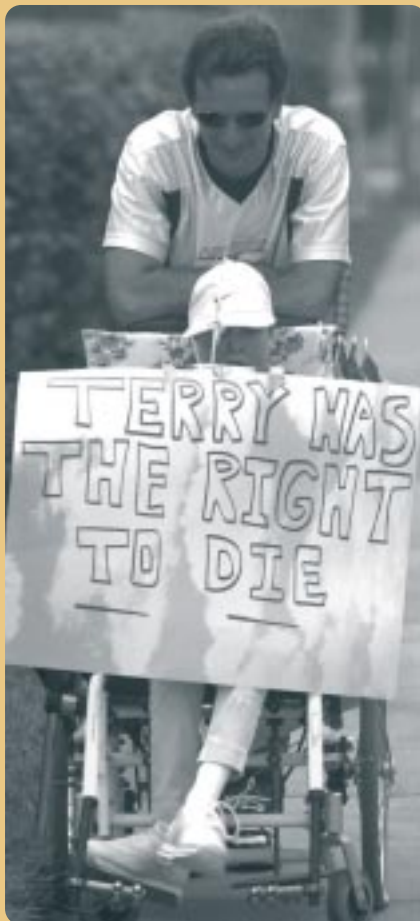
State Initiatives

in End-of-Life Care

Issue 22, October 2004

Focus: Surrogate Decisionmaking

Examining New Knowledge and Controversies about Serious Disorders of Consciousness



Photos: The Tampa Tribune



Demonstrators pictured in front of the Florida hospice caring for Terri Schiavo, who has been in a permanent vegetative state (PVS) since 1990. The legal controversy about whether her feeding tube should be removed has once again focused national attention

on the questions of who should make life-and-death treatment decisions and on what basis when patients in vegetative states have left no written advance directives. This issue of State Initiatives offers an overview of the Schiavo case in light of accepted legal and medical standards. It also presents scientific information about a new diagnosis called the "minimally conscious state." Experts say that profound disorders of consciousness will increase dramatically between now and 2050 as technology advances and baby boomers age, making decisions about whether or not to use artificial life support commonplace in these cases. Tips to help policy leaders prepare for this challenge appear on page 7.

INSIDE

- **Media Controversies and New Scientific Developments Spotlight Patients with Profound Brain Disorders**
PAGE 2
- **Current Legal, Scientific, and Medical Thinking about Vegetative States**
PAGE 3
- **Emerging Scientific Knowledge about Minimally Conscious States**
PAGE 5
- **Tips for Policymakers**
PAGE 7
- **Thorny Ethical Questions**
PAGE 8

Media Controversies and New Scientific Developments Spotlight Patients with Profound Brain Disorders

Most of us have seen Terri Schiavo in media accounts of the controversy about whether she should be allowed to die. Now 40, she has been in a permanent vegetative state, sustained by a feeding tube since 1990. Her face is haunting by any measure: her jaw noticeably slack, her lips parted but unable to speak, her eyes wide open but disturbingly fixed and expressionless.

How are we to understand her rights and the legal and moral wars swirling around her? On the one side there is her husband (and legal guardian), together with Florida's courts, asserting that she wished to be spared artificial life support; on the other, her parents, Florida's governor, and its legislature, denying that these wishes existed or are valid.

What significance do these legal challenges by Florida's executive and legislative leaders have for our constitutional privacy right to self-determination?

Important new scientific developments are raising still other questions about the treatment of patients with profound disorders of consciousness. At the center of these developments is a recently defined diagnostic category called the "minimally conscious state." Unlike patients in vegetative states, patients in minimally conscious states show some awareness of themselves and their environment. They may remain profoundly incapacitated for the duration of their lives, evolve into somewhat higher states of consciousness or, in rare instances, emerge into full consciousness with varying degrees of disability. Though there is as yet no medical cure, researchers are experimenting with a new drug regimen and considering neuromodulation, or deep brain stimulation, as potential interventions.

Are distinctions between vegetative states and minimally conscious states significant from a medical, ethical, and legal point of view? What are society's responsibilities to patients in minimally conscious states?

To promote public education and rational discussion of these questions, Last Acts Partnership (LAXP), a Washington, D.C.-based nonprofit organization devoted to improving care and caring near the end of life, convened a meeting of experts in neurology, ethics, disability issues, and end-of-life care (Houston, May 13, 2004). The featured speaker was Joseph J. Fins, MD, FACP, a clinical

ethicist, palliative care expert, and pioneer in research on the minimally conscious state and its ethical implications. For a list of other participating experts, see page 8.

This issue of *State Initiatives* discusses several major themes from Fins's presentation, supplemented with perspectives from other meeting participants and current scientific literature. Pages 3–4 encapsulate current legal and medical thinking about vegetative states. Pages 5–6 present new information about research, diagnosis, and treatment of minimally conscious states. The last two pages present a series of policy recommendations and unresolved ethical questions. ■



"We must preserve the right to refuse treatment and affirm the right to choose care."

Joseph J. Fins, MD, FACP, chief of the Division of Medical Ethics in the Department of Public Health and Medicine at Weill Medical College of Cornell University, where he serves as professor of medicine, professor of public health, and professor of medicine in psychiatry

Disorders of Consciousness: A Glossary

Brain Death: The permanent absence of all brain functions, including those of the brain stem (which controls basic functions like reflexes and breathing).

Coma: Patients in coma lack both wakefulness and awareness. Comas are typically transient: patients recover, die, or evolve to some other state of impaired consciousness.

Vegetative States: The Multi-Society Task Force on PVS, which included representatives from many of America's most prestigious neurology associations, has defined the vegetative state as a condition of complete unawareness of self and environment, accompanied by sleep-wake cycles and either total or partial preservation of areas of the brain controlling automatic functions like heart activity and reflexes (1994). PVS patients may cry or smile, but these actions are reflexive and do not reflect true awareness.

Current Legal, Scientific, and Medical Thinking about Vegetative States

Legal Foundations of the Right of Self-Determination

An individual's right to forgo medical treatment—to have it withheld or withdrawn—is well established in American medicine, bioethics, and law. Courts have affirmed this right, loosely known as “the right to die,” for patients lacking decisionmaking capacity if they have advance directives like living wills or surrogates.

The right to refuse life-sustaining treatment was established in the last quarter century by much publicized cases like those of Karen Ann Quinlan and Nancy Cruzan. Both fell into permanent vegetative states because of accidental oxygen deprivation to their brains. Neither had written advance directives and both lingered for years on artificial life support, totally unaware of themselves and their environments as legal and media battles about their fates raged. Ultimately family members acting as their surrogate decisionmakers succeeded in winning the legal right to remove artificial life support.

“We have no hesitancy in deciding,” wrote justices of New Jersey's Supreme Court on behalf of Karen Ann Quinlan, “that no external com-

pellent interest of the State could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life” (1976). The court's decision made clear that an individual's right to privacy grew stronger against the state's interest in preserving life, as treatments became more invasive and the prognosis dimmed.

“So, negative rights, the right to be left alone—so central to death and dying in America—were established through cases involving patients in the vegetative state,” says Fins.

A Supreme Court decision in 1990 defined artificially administered nutrition and hydration as medical treatments—rather than routine care—and upheld the right of self-determination for competent individuals. The Court, however, left to the states the matter of who decides and on what basis when a once-competent patient has lost capacity without having left explicit treatment wishes. Given this wide latitude, states have developed different procedural protections for implementing the right of self-determination for individuals without deci-

sionmaking capacity. Some states invest total authority in surrogate decisionmakers who are expected to honor known patient wishes and values in making treatment decisions, or—when they are not known—for making judgments in the patient's “best interest.” Other states require surrogates to have some degree of proof of patient wishes when withholding or withdrawing treatment; a few states like Florida and New York require the higher standard of “clear and convincing evidence” of prior wishes.

Diagnosis and Prognosis for Vegetative States

The best available scientific knowledge offers a rather high degree of certainty about the diagnosis and prospects of patients in vegetative states. The Multi-Society Task Force on PVS defines the vegetative state as “a clinical condition of complete unawareness of the self and the environment.”

Patients in vegetative states may seem to smile, but Fins notes that such expressions are deceiving for laypersons. “The vegetative state has been described as a state of wakeful unre-

Continues on page 4

“Persistent” versus “Permanent”

Vegetative States: A vegetative state is considered “persistent” after one month. Vegetative states are considered “permanent” after one year if caused by traumatic injuries such as a blow to the head; non-traumatic vegetative states caused, for example, by oxygen deprivation to the brain are considered permanent after three months. Guidelines for children differ.

Minimally Conscious States: Patients in minimally conscious states possess sleep-wake cycles and limited, inconsistent but definite awareness of self and environment (e.g., avoiding unpleasant stimuli, uttering intelligible sounds, or reaching for objects in a way that adjusts for their size and location).

Dementia: A degenerative neurological disorder characterized by a progressive loss of all cognitive functions with some arousal mechanisms remaining normal. Patients with advanced dementia who lose self-awareness and learned behavior often evolve into minimally conscious states and, at times, into vegetative states.

Sources: Multi-Society Task Force on PVS, “Medical Aspects of the Persistent Vegetative State—First of Two Parts,” in *NEJM* 21 (1994): 330; J.T. Giacino et al., “The Minimally Conscious State: Definition and Diagnostic Criteria,” *Neurology* 3 (2002): 58; R. Cranford, “The Vegetative and Minimally Conscious States: Ethical Implications,” *Geriatrics* 53, suppl. 1 (September 1998); N. Schiff and J. J. Fins, “Hope for ‘Comatose’ Patients,” *Cerebrum* (Fall 2003).

Current Legal, Scientific, and Medical Thinking about Vegetative States

Continued

sponsiveness. You have sleep-wake cycles, the eyes are open, and you have blinking but it's not meaningful interaction with the world. It's all reflexive. The same part of the brain that causes your heart to beat is causing these reflexes to occur. It's understandable that loved ones would assume they were seeing evidence of awareness but they aren't."

Time is critical for the prognosis of these patients. For adults the state is considered "persistent" after one month. For adults who have suffered oxygen deprivation to the brain, a vegetative state is considered "permanent" after three months; when the cause is traumatic brain injury, it is considered "permanent" after 12 months. Guidelines for children are different.

The Terri Schiavo Case

Terri Schiavo's case is much like those of Quinlan and Cruzan. Court-appointed neurologists have confirmed that Schiavo is in a permanent vegetative state brought on by oxygen deprivation to her brain following cardiac arrest. Although she left no prior written expression of her treatment preferences, the trial court, a succession of appeals courts, and Terri's own guardian ad litem have concurred that "clear and convincing [oral] evidence" of her desire to be spared artificial life support exists. After several fruitless years of seeking curative therapies, her husband (legal guardian) asked the trial court to act as Terri's proxy and order her feeding tube removed. The trial court has done so and been upheld repeatedly in appeals.

Schiavo's parents have testified that Terri is conscious and responsive, can be rehabilitated, and would not have wanted removal of the tube. They also maintain that even if she could ask for removal, they would continue their challenges because her existence gives them joy. The state legislature passed "Terri's Law" to give Governor Bush the authority to stop removal, which he has exercised.

This law and its implementing executive order were declared unconstitutional by the Circuit Court for the Sixth Judicial District. The court characterized the law and executive order as clear violations of federal and state separation-of-powers doctrine and complete deprivations of Schiavo's constitutional right to privacy (self-determination) and due process.

In a unanimous decision issued on September 23, 2004, the Florida Supreme Court affirmed the circuit court's judgment, concluding that Terri's Law "constituted an unconstitutional encroachment on the power that has been reserved for the independent judiciary" and an unconstitutional delegation of legislative power to the governor.

The fight in Florida illustrates the dangers of both disregarding clinical standards and nullifying final judicial decisions. "Diagnosis should not occur over the Internet by untrained folks and by legislators who spent 40 minutes debating the matter, as happened in the Schiavo case," says Fins. "This undermines the rule of law and the integrity of clinical diagnosis."

Removing or withholding artificially administered nutrition and hydration (ANH) has reemerged as an issue in the Schiavo case. Those who oppose the practice typically define such feeding as routine care. Yet defining ANH as a treatment is a judgment based in science and affirmed by the Supreme Court. "To define it otherwise is to fly in the face of reality," says Ron Cranford, chief of neurology at the Hennepin County Medical Center and professor of neurology at the University of Minnesota Medical School. "There is an overwhelming consensus that ANH is a medical treatment: it requires consent; skilled clinicians must implant and remove the PEG [feeding tube]; it can have serious complications; and removal or withholding causes dehydration, not some terrible process of starvation. Most patients and loved ones don't want feeding tubes."

Polls confirm that most Americans don't want the right to refuse treatment denied to patients in vegetative states or to their spouses. A 2003 Gallup poll found that 80 percent of respondents believed that a spouse should be permitted by law to decide to let a partner in a permanent vegetative state die. The poll showed no major differences based on religion, ideology, or political affiliation. A 2003 Florida poll conducted by *The Tampa Tribune* and *The St. Petersburg Times* had similar findings.

While treatment decisionmaking for patients in the vegetative state raises wrenching emotional issues, the broad consensus among legal, clinical, and ethics experts, together with the popular support for self-determination in these cases, offers a relatively sound basis for policymaking.

Decisionmaking for patients in the minimally conscious state is far less charted territory. ■

For a legal timeline and key court findings on the Terri Schiavo case, go to: www.miami.edu/ethics2/schiavo/timeline.htm.

Emerging Scientific Knowledge about Minimally Conscious States

Serious Brain Impairment: A “Silent Epidemic”

Many experts see brain impairment as a continuum, with brain death and the permanent vegetative state at the lower end and moderate disability at the higher end. This continuum includes a large and growing number of Americans (see sidebar).

Traumatic brain injury due to motorcycle, automobile, and sporting accidents is a leading cause of both vegetative and minimally conscious states. “Traumatic brain injury is a silent epidemic,” says Fins. “The problem is underfunded and underappreciated as a genuine threat to public health. It is the leading cause of disability in children and young adults.”

Strokes, degenerative diseases like advanced Alzheimer’s, and metabolic disorders also often result in minimally conscious states and, at times, in permanent vegetative states. “More than 50 percent of aging baby boomers are expected to have cognitive disabilities if they live past age 85, so the rate of severe disorders of consciousness will soon increase dramatically,” says Joanne Lynn, MD, MA, MS, The Washington Home Center for Palliative Care Studies. “Very severe dementia will become a major cause of the minimally conscious state.”

Diagnosis and Prognosis for Minimally Conscious States

According to the Aspen Criteria—consensus-based guidelines developed by an international delegation of experts (1995–2000)—patients in the minimally conscious state have definite but limited and fluctuating awareness of self and their environment. They may be able to follow simple commands, give appropriate yes or no responses to questions, make intelli-

gible verbalizations, or move or feel in response to environmental stimulation: avoiding physical obstacles in a wheelchair, crying in response to the emotional content of language, pursuing moving objects with their eyes, or responding to threatening gestures. Such states may be either permanent or transient.

If patients evolve from vegetative states into minimally conscious states in the first few months after traumatic head injury, there is a strong rationale for aggressive treatment until the final outcome is determined, says Cranford. The chance for recovery diminishes over time: most patients in minimally conscious states more than a year after injury remain severely disabled, say many leading experts.

A 1997 study by Giacino and Kalmar confirms that prospects are much better when both time and type of injury are on the patient’s side. Researchers found that, of 104 patients who were in vegetative and minimally conscious states *within one year after injury*, patients in minimally conscious states showed more continuous improvement and attained significantly more favorable outcomes than those in vegetative states. Half of those in minimally conscious states due to traumatic brain injury showed none to moderate disability at 12 months.

The “Neglect Syndrome”

In an article in *Nature Reviews Neuroscience*, Fins argues that winning the right to self-determination has produced important social benefits, but also unwittingly contributed to the therapeutic neglect of patients in minimally conscious states. “The right of self-determination was established in PVS patients for whom it seemed nothing could be done. This has led

Continues on page 6

A Silent Epidemic: Facts and Figures

The growing brain injury problem merits more investment in research, prevention, and treatment, say experts.

Incidence (USA)

10,000–25,000

adults currently in vegetative states

6,000–10,000

children currently in vegetative states

100,000–300,000

people in minimally conscious states

1.5–2.0 million

people stricken annually with traumatic head injuries

2.5–6.5 million

overall prevalence of traumatic brain injury

4.5 million

number of people with Alzheimer’s disease in 2000

11.3–16 million

number of people likely to have Alzheimer’s disease by 2050

Costs (USA)

\$600,000–\$1,875,000

projected average per person lifetime costs of care for traumatic brain injury

\$1-7 billion

estimated annual costs for care of all children and adults in vegetative states in 1994

\$9.1 billion

cost of all new annual traumatic brain injury cases

\$48 billion

total yearly cost of all traumatic brain injury cases

\$61.1 billion

annual cost of health care for all Alzheimer’s sufferers plus indirect costs for lost productivity, worker replacement, and absenteeism related to caregivers of Alzheimer’s sufferers

Sources: J. J. Fins, “Constructing an Ethical Stereotype for Severe Brain Injury: Balancing Risks, Benefits and Access,” *Nature Reviews Neuroscience* (April 2003); “NIH Consensus Development Panel on Rehabilitation of Persons with Traumatic Brain Injury,” *J. Am. Med. Assoc.* 282 (1999); N. Schiff and J. J. Fins, “Hope for ‘Comatose’ Patients,” *Cerebrum* (Fall 2003); Multi-Society Task Force on PVS, “Medical Aspects of the Persistent Vegetative State—First of Two Parts,” *NEJM* 21 (1994): 330; R. Cranford, “The Minimally Conscious State,” *Neurology*, (February 2002); <http://www.alz.org/aboutad/statistics.asp>.

Emerging Scientific Knowledge about Minimally Conscious States

Continued

to a kind of therapeutic ‘hopelessness’ for severely brain-injured patients as a group. Then you have the advent of technology and the mid-century ‘therapeutic lobotomy’ scandals creating very aggressive patient protections. Ironically, the combination of ‘hopelessness’ and these protections has led to neglect.”

The Terry Wallis Case

The case of Terry Wallis—which Fins and his colleague, Nicholas Schiff, MD, have studied—vividly illustrates the neglect syndrome. Twenty-year-old Terry Wallis fell victim to a severe brain injury in 1994 when the car he and a friend were riding in plunged into a creek. He was never evaluated by a neurologist because his parents couldn’t afford the assessment fees, and Medicaid would not pick up the costs. For 20 years he was consigned to a nursing home without follow-up or treatment. Throughout this period of presumed “unconsciousness,” he had shown signs of awareness of self and environment, responding to simple questions, for example, with nods of his head or meaningful sounds. Then in 2003, he spontaneously uttered the words “Pepsi” and “mom” and began to develop some fluency of language. While media reports inaccurately represented his initial diagnosis as permanent coma or permanent vegetative state, he had actually emerged from a minimally conscious state after passing through coma and a brief period in the vegetative state, according to Fins and Schiff.

Addressing neglect at a clinical level will require improved diagnostic clarity, says Fins. “Diagnostic clarity is important because it helps us determine whether medical treatment will be useful or futile.” Fins also urges change in the widespread practice among physicians of conflating differ-

ent disorders of consciousness. This practice should be replaced by rigorous clinical assessments that make use of known diagnostic distinctions, he says.

Transcending the neglect syndrome will also require a cultural shift away from our tendency to let ideological appeals outweigh careful scientific judgment and to think in either/or terms, says Fins. “Diagnosis shouldn’t become a values choice, and we must avoid an ideological battleground that either undermines the right to refuse treatment or threatens the right of persons with disabilities to benefit from advances in research and care.”

Prospects for Treatment

Although there is currently no therapy shown to have restored consciousness for those in minimally conscious states, there is some clinical and experimental data suggesting that neuromodulation—an emerging technology of deep brain stimulation (DBS) involving low-level electrical stimulation of the thalamus—may one day be used to treat such severe disorders. DBS has been approved by the FDA for treatment of drug-resistant Parkinson’s and is the standard of care for that illness. It is also being used successfully to treat epilepsy and chronic pain.

On another front, the drug amantadine hydrochloride is being tested on a group of patients in minimally conscious states, in a new trial funded by the National Institute on Disability and Rehabilitation Research.

Barriers to Needed Research

Much more research is needed to determine the prevalence of the minimally conscious state, its natural history, and predictors of emergence and recovery. Such research will ultimately

allow for counseling, prognostication, and effective treatment. Yet the path to new knowledge is being impeded, experts say, by well-intentioned but excessive restrictions on neuro-psychiatric research.

At the heart of the problem is the thorny issue of consent to do research on patients without capacity to consent. “There is a long, well-documented history of discounting the views and needs of people with disabilities,” says Lex Frieden, professor of physical medicine and rehabilitation at Baylor College of Medicine and senior vice president of The Institute for Rehabilitation and Research. “That creates skepticism that their interests will be protected by judges, legislatures, or surrogates of any kind when treatment or research is at issue.”

Clearly, the path to an acceptable balance between protecting patients, on the one hand, and ensuring their access to the benefits of research and treatment, on the other, must be found or the neglect syndrome will continue to diminish the recovery prospects of people with profound disabilities like the minimally conscious state. ■

“There is a long, well-documented history of discounting the views and needs of people with disabilities. That creates skepticism that their interests will be protected by judges, legislatures, or surrogates of any kind.”

Lex Frieden, professor of physical medicine and rehabilitation at Baylor College of Medicine

Tips for Policymakers

Demographic trends, expanding life expectancies, and advances in medicine and technology will greatly increase the incidence of vegetative and minimally conscious states. How should policymakers prepare to address these future needs? Here are several policy tips and considerations that emerged during the Houston discussion:

Recommendation	Problem	Policy Response
Increase the Utilization and Scope of Advance Directives for Older Persons and Those Who Are Ill, in Particular.	No more than 25 percent of Americans have advance directives, though these tools can help safeguard patients' rights, prevent trauma for loved ones, and forestall divisive public controversies.	Policymakers and opinion leaders must find ways to make advance directives—particularly durable powers of attorney for health care—a cultural expectation and, in certain circumstances, a requirement (e.g., the State of Maryland's Department of Health makes use of these tools a quality indicator in nursing home regulation).
	Advance directives often deal only with terminal conditions, yet many Americans would not want to be maintained on artificial life support if they were in a permanent (but not terminal) vegetative or minimally conscious state.	Average citizens need to be encouraged to identify treatment preferences should they be struck with such disorders, and policy needs to support their preferences. "We should prepare people for disability, especially loss of consciousness, but we don't," says Lex Frieden, professor of physical medicine and rehabilitation at Baylor College of Medicine.
Support Balanced Treatment Practices and, in the Absence of Advance Directives, Family Decisionmaking.	As new diagnostic categories like the minimally conscious state enter public debate, extremists on both sides might seek to conflate clinical distinctions between permanent vegetative states and more hopeful minimally conscious states in order to erode the hard-won right to forgo life-sustaining treatment or the right to choose treatment.	Policymakers should protect both the right to choose treatment and the right to refuse it, recognizing that neither overtreatment nor undertreatment is desirable. Time-limited treatment trials are useful when there is high uncertainty about treatment benefits (for more on time-limited trials, go to www.medicaring.org , select <i>Handbook for Mortals</i> image, then "forgoing treatment"). When advance directives are absent, appropriate surrogates, especially loved ones, should be given great deference in treatment decisionmaking.
Make Policy Based on Science and Honor Existing Decisionmaking Laws and Processes.	Legislatures are vulnerable to pressure from articulate and powerful interests whose views do not represent the popular will or conform to the best scientific and legal thinking.	Legislatures should avoid case-by-case lawmaking and let careful scientific judgment and existing health care decisionmaking law outweigh purely emotional and ideological appeals ("what is in the Constitution," noted the Florida Supreme Court in the Schiavo case, "must always prevail over emotion").
Review Laws Concerning the Removal of Life-Sustaining Treatment.	Some state laws are so restrictive about the removal of life-sustaining treatments like artificial nutrition and hydration (ANH), say clinical experts, that surrogates might avoid authorizing ANH in the first place for a patient in a minimally conscious state in order to avoid a battle over withdrawal later on.	Such overly-restrictive policies could have the unintended consequence of depriving patients with serious but transient disorders of consciousness the chance to recover. Lawmakers should review and consider modifying such laws.
Facilitate Research on the Minimally Conscious State.	Progress in treating minimally conscious states depends on research that is currently impeded by excessive research restrictions, say Fins and others.	Policymakers could help support research authorization protocols that strike a better balance between patient protection and patient access to the improved care and treatment that more research could provide.
Consider Funding Better Prevention and Treatment of Profound Brain Impairments.	Fins argues that patients with serious brain impairments like the minimally conscious state are being neglected even though recovery is possible for some and potential treatments are now being evaluated.	Policymakers should consider the costs and benefits of funding more research, prevention, and treatment. In doing so, issues of distributive justice should not be ignored: many people now institutionalized with noncognitive disabilities such as paralysis, as well as some elderly patients in nursing homes, routinely receive substandard care; improving their care should also be a concern.

Thorny Ethical Questions

For all their power and suggestiveness, the new findings about minimally conscious states generate more questions than answers at this juncture.

How Useful Is the Minimally Conscious State as a Diagnostic Category?

The most radical question is whether the new diagnostic category represents a meaningful distinction in ethical terms. Alan Shewmon, pediatric neurologist at the University of California, Los Angeles, argues that this broad label creates the mistaken assumption that there are sharply different ethical implications for decisionmaking regarding the minimally conscious state and other brain-based disorders. In his view, impairments of consciousness exist on a continuum without sharp distinctions, according to a report in the *UK Guardian* (April 15, 2004).

What Are the Risks Associated with Partial Cures?

For those who believe the category is useful, there are questions about treatment for patients who are not likely to recover appreciably. Their states often differ little in terms of functional ability from patients in permanent vegetative states. What are the ethical implications of raising their level of consciousness only marginally? Such partial cures could simply make

patients more aware of their immobility, dependency, and discomfort—thereby increasing their suffering—say Cranford and others. Are there clinical circumstances in which aggressive treatment for those in minimally conscious states is not warranted? Fins maintains that such patients are part of the human community and that conversations with loved ones about diagnostic distinctions and treatment options should be conducted to preserve and inform choice.

What Are the Implications of “Recovery” for Caregivers?

Even miraculous awakenings may bring patients and their loved ones the burden of confronting identities and lives transformed by injury. As more diagnostic distinctions and treatments emerge, what are the implications for family caregivers? “By attempting treatments that have unknown or marginal benefit to people in minimally conscious states, we are likely to increase the burden on patients and family caregivers,” says Myra Christopher, president and CEO of the Center for Practical Bioethics. “Unfortunately, as a society, we continue to be willing to fund aggressive and often expensive interventions, but we are unwilling to adequately fund services needed by family caregivers.”

Experts at the Houston Meeting

Eduardo Bruera, MD

Chair of the Department of Palliative Care and Rehabilitation Medicine at the University of Texas M.D. Anderson Cancer Center

Myra Christopher

President and CEO, Center for Practical Bioethics

Ron Cranford, MD

Assistant Chief in Neurology at the Hennepin County Medical Center, Professor of Neurology, University of Minnesota Medical School, and Faculty Associate, Center for Bioethics, University of Minnesota

Joseph J. Fins, MD, FACP

Chief of the Division of Medical Ethics in the Departments of Public Health and Medicine at Weill Medical College of Cornell University, where he serves as Professor of Medicine, Professor of Public Health, and Professor of Medicine in Psychiatry

Lex Frieden

Senior Vice President at The Institute for Rehabilitation and Research and Professor of Physical Medicine and Rehabilitation at Baylor College of Medicine

Joanne Lynn, MD, MA, MS

Director of The Washington Home Center for Palliative Care Studies and Senior Researcher with RAND Health

Mary Meyer

Former Vice President for Consumer and Constituent Services, Last Acts Partnership (LAXP)

Karen Orloff Kaplan, MPH, ScD

Former President and CEO of Last Acts Partnership (LAXP)

Myrna Peralta, MSW, JD

Coordinator of Rallying Points National Resource Center on Diversity in End-of-Life Care and President of ALTA Consulting Group

Judy Peres, LCSW-C

Former Vice President for Policy and Advocacy, Last Acts Partnership (LAXP)

Sister Mary Roch Rocklage, RSM

Chairperson of the Board of Directors of Sisters of Mercy Health System (Mercy)

True Ryndes, ANP, MPH

President and CEO of the National Hospice Work Group and Vice President for Public Policy and Advocacy at San Diego Hospice and Palliative Care

Gary Stein, JD, MSW

Executive Director of New Jersey Health Decisions

Information about the Series

“Surrogate Decisionmaking: Examining New Knowledge and Controversies about Serious Disorders of Consciousness” is the twenty-second in a series of briefs profiling promising policies and practices in end-of-life care.

Executive Editor:

Myra Christopher

President and CEO, Center for Practical Bioethics
Past Director, Community-State Partnerships National Program Office

Researcher and Writer:

Jeri Spann

President, Spann Communications, LLC, Pittsburgh, PA

Designer:

Rob Henning

Rob Henning Design, for Spann Communications, LLC

Editorial guidance for the *State Initiatives* series is provided jointly by the Center for Practical Bioethics (CPB) and The Robert Wood Johnson Foundation. The foundation supplies series funding.

To Order Publications

To order additional copies of this publication, phone, write, or fax CPB, using the contact information below, and reference **Issue #22** in your request.

Previous issues of this series are available. CPB will provide a list of available back issues upon request. Copies of all briefs are also available online at www.practicalbioethics.org.



Center for Practical Bioethics

Town Pavilion
1100 Walnut, Suite 2900
Kansas City, MO 64106-2197

Telephone 1 (800) 344-3829
1 (816) 221-1100

Fax 1 (816) 221-2002

E-mail bioethics@practicalbioethics.org

Web site www.practicalbioethics.org

CPB directed the Community-State Partnerships national program office (1998-2003), a program supported by The Robert Wood Johnson Foundation. CPB continues to provide resources and education about ethical issues in health and health care to advocates, policymakers, professionals, and consumers.