

Bioethics *in brief*



September 2005

UNIVERSITY HOSPITAL OF SUNY UPSTATE MEDICAL UNIVERSITY

SYRACUSE, NEW YORK

IN THE SPOTLIGHT



Law Reform After Schiavo

In the aftermath of the protracted, highly public legal battle over the fate of Terri Schiavo, more people across the country have reportedly completed advance directives to take charge of decisions near the end of life. More of us are talking with family, friends, and health care professionals about how we die. Sadly this positive legacy is somewhat undercut by another storyline. The personal and bitter family battle that shaped Ms. Schiavo's tragedy ultimately made her the symbol of a cause in a politicized national debate of unprecedented proportion. For better or worse the *Schiavo* case has changed the way we think about and debate ethical issues surrounding the dying process. Many are asking whether this saga will bring in its wake significant changes in the legal rules for dying.

Looking at the case itself, the numerous court rulings in *Schiavo* brought no change in existing law. To the contrary, the case reaffirmed that Florida law shares the consensus positions that we each have a constitutionally protected right to refuse life-sustaining treatment, including artificially provided fluids and nutrition, and that close and caring family members may exercise this right on behalf of an incompetent loved one. Florida's embrace of the clear and convincing evidence standard of proof of the patient's wishes places the sunshine state with a handful of other states (including New York) that represent a minority departure from the more family-friendly, less demanding rules of most states (for example, proof by a preponderance of the evidence). Still, Florida courts repeatedly found that Terri's husband had met this burden and that he conducted himself in good faith, legitimating the time-honored judicial process (including a highly unusual number of appeals) for challenging his authority and the

continued, next page



Clinicians & Military Prisoner Abuse

In August 2004, *The Lancet*, a leading British medical journal, printed an article by physician-ethicist Steve Miles alleging that military physicians and medics were involved in the torture of military prisoners in Abu Ghraib in Iraq. This summer, the *New England Journal of Medicine* and *The New York Times* published similar allegations of physician complicity in interrogations of prisoners thought to be affiliated with al Qaeda or the Taliban who are imprisoned in the US military facility in Guantánamo, Cuba. In July 2005, Miles followed up with a detailed analysis of inadequate medical investigations of deaths among Iraqi and Afghan prisoners of war (published in the on-line journal *Medscape*). Reports from these facilities allege that, at times, physicians, medics, and other military personnel:

- provided intelligence officials with medical information about prisoners' fears and advice on ways to increase stress, in order to aid interrogations;

continued, page 3

Bioethics *in brief*

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Bioethics in Brief is a newsletter of the Center for Bioethics and Humanities, in cooperation with University Hospital's Ethics Committee.

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—continued from page 1

Law Reform After Schiavo

weight of the evidence of the patient's wishes. Subsequent proceedings involving the Florida governor's intervention, and later congressional involvement, solidified these foundations and sent a further important message: the constitutional separation of powers directs the executive and legislative branches not to interfere with final adjudications of the judicial branch of government in individual cases. *The case is discussed in greater detail on pages 4 and 5.*

With the death of Terri Schiavo, and litigation ended, some state legislatures have turned their attention to law reform. In several states bills have been introduced to require more rigorous proof of a patient's wish to forgo a feeding tube, a rule that already exists in some states. Some have feared that post-*Schiavo* legal change such as this would necessarily be directed to limiting patient and family rights and eroding the national consensus, or perhaps states would shy away from addressing pressing but now possibly more controversial issues.

These apprehensions may be misplaced; indeed there are signs the national debate has had the opposite effect. Here in New York our legislature this past term gave serious consideration to the Family Health Care Decisions Act, a bill that would remove some legal obstacles for families facing end-of-life decisions, though the bill never came to a full vote. In Washington, D.C., at least two bills aim to encourage awareness, discussion, and completion of advance directives, building on the Patient Self-Determination Act of 15 years ago. The bills also propose Medicare coverage for end-of-life consultations.

To limit the effect of the *Schiavo* case to how we die would be myopic. The "culture of life" sloganeering pressed by some participants in the national debate, including elected officials in Florida and the nation's capitol, is intended to build a bridge to issues at the beginning of life, specifically to resonate with opponents of abortion and of the creation and use of embryos for stem cell research. Meanwhile some states have moved forward with support of embryonic stem cell research, as have some members of Congress, perhaps suggesting that early concerns of a chilling effect on progressive policy have been exaggerated. The controversies are far from settled.

—Robert S. Olick

Five Wishes

Aging with Dignity is a website currently in the news for its Five Wishes document. Supported and distributed by a grant from the Robert Wood Johnson Foundation, the Five Wishes document attempts to address a person's medical, personal, emotional, and spiritual needs. By filling out the document, a person can let family and physicians know the following:

- The person you have chosen to make health care decisions for you in the event you cannot make them for yourself.
- The medical treatment you want as well as the medical treatment you do not want.
- What kind of comfort care you want.
- How you want people to treat you.
- What you want your family and friends to know.

The document provides a concrete way for discussions to begin among family members or between patients and physicians. It does not use medical language; it tries to speak to people in ordinary, everyday language about subjects we usually try to avoid: aging, dying, death.

Some states do not recognize the Five Wishes as a legal document, but it still is valuable as a tool for organizing one's thoughts on these topics.

—continued from page 1

Clinicians and Military Prisoner Abuse

- did not provide necessary medical treatment for traumatic injuries;
- delayed or falsified death certificates, stating that the inmate died of natural causes when there was clear evidence of torture as the cause of death.

In one particularly egregious case cited by Miles, clinicians revived a patient left unconscious after a beating by military officials and then left him in the room where the physical abuse subsequently continued.

Such behaviors are clear violations of the Hippocratic Oath, where physicians promise, "I will use treatment to help the sick according to my ability and judgment, but never with a view to injury and wrongdoing." Such activities seem worlds away from the clinical realm in which we practice. How can we understand the choices of these fellow clinicians?

As an ethical issue, such problems are often analyzed as an example of divided loyalties, when clinicians not only are responsible for their patients' welfare, but also must answer to another entity (in this case, the military). While the life of a military physician in time of war is a dramatic example of dual loyalties, less dramatic conflicts may arise for physicians employed by prisons, athletic teams, industry, or managed care organizations, to name a few examples. These physicians all have responsibilities to an organization, and, at times, the responsibility to the organization may collide with the physician's sense of what is best for the individual patient.

Another way to understand how presumably good clinicians can come to act in such egregious ways is to look at the concept of "moral climate." People, especially those who do not believe they hold ultimate responsibility, may come to assume the mores of those around and above them. They may become accustomed to behaviors that change their sense of right and wrong. Leaders in an organization have a particular responsibility in shaping this moral climate, setting examples, review mechanisms, educational programs, support structures for employees, and policies that make clear the expectations.

But ultimately, the clinician caring for the patient is responsible for his or her actions. Physicians who falsify records for the State's benefit, who harm their patients, or who assist others in harming them, have broken their oath and most fundamental professional commitments, bringing shame on themselves and the profession.

—K. Faber-Langendoen

Reflections on the *Schiavo* Case

Editor's Note: While we generally do not print opinion pieces, we believe the following article is a useful commentary on an issue of great interest to our readers.

—DN

The multiply tragic story of Terri Schiavo, which culminated in her death on March 31, 2005, after removal of her feeding tube is not just about Terri Schiavo. It is about all of us. A terrible event, years ago, destroyed her cerebral cortex; she became irreversibly incapable of consciousness. Yet she has become important to our private lives and our lives as citizens.

Schiavo, 41 at the time of the intense media attention and public debate last spring, was in a persistent vegetative state (PVS) since 1990, due to massive brain damage when her heart stopped. She underwent rehabilitation for years, without improvement. Since 1993, her husband was embroiled in a dispute with his in-laws, the Schindlers, about treatment. After waiting eight years for Terri to improve, he asked the Court in 1998 to allow her feeding tube to be removed; her parents protested, filing suit.

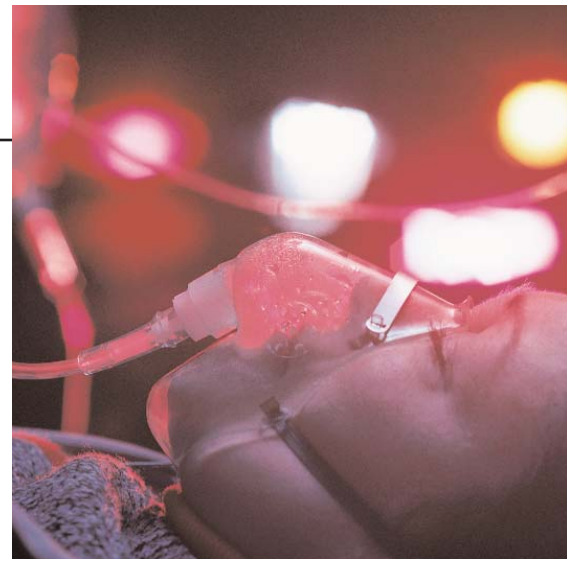
Since 1993, the case was addressed in over 25 court proceedings in Florida State Court and federal courts, including the US Supreme Court. The Florida Court repeatedly upheld Mr. Schiavo's right to make medical decisions for his wife, despite the Schindlers' pleas to remove him. In 2000, after testimony from several family members, the Court found that Ms. Schiavo had made clear and

convincing statements that "she would want the tubes and everything taken out" if she were in a coma. Her statements were in lay terms; she spoke not of artificial nutrition and persistent vegetative states, but of coma, tubes, machines, being a burden, and letting go.

A solid consensus in this country – that people have the right to refuse unwanted medical treatment – arises from our culture of freedom and pluralism. If a person becomes unable to make her own medical decisions, someone who knows her can be appointed to speak on her behalf. Most states allow people to appoint someone for this role (a "health care proxy"). For the 75 percent of people who do not do so, doctors and courts look to family. Recognizing marriage's value in society, spouses are generally given precedence over parents of adult patients.

This sad case prompts serious debate about individual liberties and medical care. It challenges clinicians, politicians, and citizens. In the public debate about Ms. Schiavo's fate, confusion about medicine, political wrangling, and religious rhetoric hijacked this case.

Substantial medical misinformation confuses the debate. According to court testimony, Ms. Schiavo was repeatedly diagnosed by physicians as being in a PVS. A patient with PVS is not the "sleeping beauty" of fairy tales, but has periods of being awake without being aware. In PVS, the brain stem functions, allowing patients to breathe and



have some reflexes. Eyes and limbs move involuntarily, but without awareness.

Widely broadcast home video clips made three years ago of Ms. Schiavo show a few minutes from 4.5 hours of videotape. Despite their compelling appearance, they provide no evidence for determining whether Ms. Schiavo is in a PVS. Further, old video tells us nothing about her condition in the months prior to her death.

The last weeks of Ms. Schiavo's life brought warnings of the gruesome death patients suffer when feeding tubes are removed, with talk of starvation and cruelty. Until feeding tubes appeared 40 years ago, generations of people slipped away gently when no longer able to eat or drink. A patient unable to eat, with no artificial nutrition or hydration, usually dies in 3 to 14 days – not from starvation or malnutrition, but dehydration. Dying patients without neurological injury rarely complain of thirst or hunger. They become weaker, sleepier, and eventually their breathing becomes irregular and their hearts stop. With attentive medical care, the mouth is kept moist, and pain and anxiety are treated with medications. A PVS patient's brain cannot comprehend or experience pain.

Political intrusion also hijacked this case. As citizens, we are empowered, protected, and constrained in various ways by government action. We want liberty to live as we judge best, yet we want government to serve our purposes when collective action is needed. Private choices and public concerns are always contested and delicately balanced; major shifts in that balance disrupt society pervasively. This case was seized as an opportunity to increase the scope of government's role in medical decisions.

In our complex and richly diverse democracy, there is a delicate tension between state and federal powers; this case was used as an occasion to increase the role of federal power over that of the states. And our famous balance of powers among the legislative, judicial, and executive branches – a glory of American democracy – was also rent by this case. We have long benefited from the stability that comes from deliberations that are fair and thorough, even knowing that we will each dislike an outcome from time to time. If we attack the process whenever we lament an outcome – with the complicity of political opportunists in government – the balance of powers dissolves as the separation of the governmental branches erodes.

This case also raised concerns about doctors' professional ethics. In Ms. Schiavo's final month, three politicians sought to don their white coats as they governed. Senator Frist, a surgeon, declared that Ms. Schiavo was not in PVS after reviewing an hour of videotape. Representative Weldon, an internist, sought permission to examine her to evaluate her

medical condition. Representative Gingrey, an obstetrician, opined that she could improve, given appropriate treatment. None of these efforts withstands scrutiny. Diagnosing or predicting outcomes without firsthand knowledge of the situation is a breach of medical ethics. A politician, even a physician, has no standing to examine a patient not under his care who has not sought his advice. Physicians take oaths that the individual patient's welfare is their primary concern; physician-politicians ought not use their medical pedestals for political purposes.

Although the Christian "religious right" claimed this issue, arguing for the sanctity of life no matter how debilitated, the broad mainstream of Christianity was too silent. Religious voices are crucial in American public discourse. Those who profess Christianity should have made clear that their religion – right, left, and center – embraces the hope of a future life. The morality of decisions to refuse treatment and of allowing people to make their own decisions must not be hijacked by a small segment of a single religion in a free and religiously diverse society.

Whatever your beliefs, there are steps to protect yourself against decisions you would not want, should you lose decisional capacity – and not just for the elderly or ill. Many of the classic cases, like Schiavo, were young when tragedy destroyed their capacity to decide. It may be hard to decide what you prefer, in part because we all avoid thinking about such terrible possibilities. Even deciding is not enough; you must also choose whom you trust most to implement your decisions and respect your values, especially if something

unpredictable happens. Discuss your choices with that person. Record them clearly in writing. Make them widely known to those close to you. Appoint a health care proxy. It does no good to have documents in a drawer no one opens until too late. You don't need a lawyer; you need common sense and the courage not to procrastinate.

That takes care of you as a patient, but not as a citizen. Your options may get better or worse, as these issues reappear in the courts and legislatures. Democratic governance requires informed judgment and civic engagement, so follow the news critically, shun the bad arguments, and assert your political voice.

Shouldn't we bring the same zeal spent on the Schiavo case to deep problems in our world that shorten lives and cause suffering daily? The poor die young. African-Americans have worse health outcomes across the board. Many elderly suffer strokes, heart attacks, and chronic pain because they cannot afford medications. Millions of Africans die from lack of clean water or HIV drugs. This silent tsunami of untimely death and suffering of the vulnerable needs the same critical look and political energy that this case received. A "pro-life" ethic should extend to the many whose lives are imperiled by our current lack of attention, compassion, and political will.

If we heed these calls, then the lessons of Schiavo will not be wasted on us.

K. Faber-Langendoen and Samuel Gorovitz (adapted from an article written for the *Syracuse Post-Standard*, March 27, 2005)



When the Professional Is Also the Patient's Family Member

Acute care nurses are adept at dealing with patients and their families at a most stressful time; they skillfully assess needs, carry out the plan of care, and provide support to the patient and family in a professional manner. However, when a nurse's own family member becomes a patient with a serious illness or injury, professional caring and personal caring intersect. What happens when a nurse, so used to being the caregiver and support for patients and their families, suddenly finds him/herself in the role of family member of a patient? This situation can create ethical tensions for the nurse.

Privacy and Confidentiality

An essential part of professional nursing is the assurance of confidentiality of each patient's health information. When a family member is being treated at a nurse's hospital, however, boundaries may become blurred. Because of their knowledge base, nurses often do ask more questions and want more information than would ordinarily be given to family members. Colleagues may

feel they can and should share such information when they would not do so for family members of other patients.

While there is an ethical prohibition against a professional accessing the medical records of a patient with whom they have a personal relationship, a conversation between professional colleagues may seem to both sides a reasonable and even useful medical tool. Nurses need to think about this before asking for confidential information from their colleagues or before giving confidential information to their colleagues that they would not give other family members of a patient.

The maintenance of privacy, both for the patient and for the nurse who is a family member, is another cause for concern. Quick visits from colleagues to show support are appreciated but can put a strain on the nurse's ability to have private time with family.

Professional vs. Private Roles

When the patient is family, a nurse may have his/her own need to provide care; making the patient

comfortable can be an expression of love. The nurse may also think, who knows the patient's preferences better? However, the nurse's presence at the bedside might be a stressor for those nurses actually charged with providing care. On the other hand, the nurse whose family member lies ill has the added burden of maintaining a professional demeanor around colleagues when inside the nurse may be falling apart.

Sometimes professional colleagues assume that the nurse can and will take responsibility for care beyond what the expectation would be for other family members, perhaps believing that the nurse already knows all there is to know about this disease or injury. Colleagues can tend to bring all information to the nurse first; family members can delegate decision-making to the nurse even when the nurse does not wish that responsibility. Nurses whose family members are patients describe the burden of acting as the spokesperson, the messenger, and interpreter for both family and colleagues, a continual sense of a dual identity that complicates their response to the loved one's illness.

continued, next page

When the Professional Is Also the Patient's Family Member

Emotional Conflicts

Their professional training and experiences enable acute care nurses to stay calm in life-threatening emergencies and emotionally charged situations. Being able to mask emotions while providing patient care is expected, yet when confronted with the illness of a loved one, a nurse feels the same emotions that any other family member would feel. However, the presence of one's colleagues can strain or inhibit the nurse's ability to react honestly to the situation.

For example, if the nurse finds instances where the family member's care does not measure up to institutional standards, a heightened stress occurs. Registering complaints about care is difficult when colleagues are involved.

Often, colleagues have provided the nurse-family member with special favors, treatment for the patient that displays the colleagues' solidarity; how then can the nurse negotiate his/her dissatisfaction without alienating the people with whom he/she works?

Conclusion

Obviously, nursing ethics do not change just because a nurse's family member lies ill in the nurse's hospital. Compassion and respect and the highest quality of care for every patient are the nurse's priority. It is important to consider, however, that perspectives and needs may seem different from each side of a patient's bed, and the nurse who is a family member may have to move smoothly from one side to another. Colleagues who realize the often complicated dance that may ensue from such dual identities are much appreciated.

—Barb Fero

University Hospital Ethics Committee Supports State and Hospital Regulations Regarding DNR Orders in the Operating Room

The University Hospital ethics committee presented an Anesthesia Grand Rounds in 2004 on "DNR in the OR" to reinforce New York State and UH policies mandating that DNR orders be maintained in the OR if the patient or surrogate refuses to suspend or revoke an existing DNR.

The ethics committee also supported a change in the hospital's surgical consent form that recognizes patient autonomy by mandating that patients undergoing surgery who want to be DNR may keep DNR orders in place. Surgery may not be denied to the patient, nor may the operating room team unilaterally institute CPR in the case of a cardiac arrest. The recommended process of reviewing the DNR order with the patient, called "required reconsideration," falls to the surgeon but may be delegated to the anesthesiologist and is supported by the professional organizations of surgeons, anesthesiologists, and operating-room nurses.

Requests by patients or surrogates for DNR during surgery are unusual; most requests are made by terminally ill patients who are aware of the poor success rates of CPR for people in their condition. Their request for DNR means they would accept death from cardiac or pulmonary arrest, although they do not seek it. Some physicians may have moral objections to performing surgery or providing anesthesia in the presence of a DNR order, because some medications or procedures used in the operating room may cause an arrest, and also because most people undergoing surgery in the OR are already manually or mechanically ventilated.

The conscientious objections of physicians will be honored but should be rare, and these physicians will have the responsibility to help the patient obtain the services of another physician. All University surgeons, anesthesiologists, and operating-room nurses have been notified of the New York State regulations and hospital policy.

It is important to discuss with the patient or surrogate whether the patient would want CPR if the patient were to be terminally ill, permanently unconscious, if resuscitation would be very burdensome, or if CPR was felt to be futile. Individual patients with capacity may have other reasons for putting a DNR order in place. Patients with legally valid non-hospital DNR orders or those with DNR orders from nursing homes will have their DNR orders accepted in University Hospital's emergency room or upon admission to University Hospital.

—Joel Potash

Talking to Patients About Death

Terri Schiavo's case brought to the fore the importance of having advance directives and health care proxies for all patients, no matter their health status. Often when a patient is in the end stage of a disease, doctors and nurses are so focused on cure that they neglect to discuss advance directives while the patient has the capacity to do so. Don't wait until the patient is in the ICU before talking to him or her about end-of-life decisions.

Ask your patients now if they are ready to talk about the dying process, with you and/or other health caregivers and with their loved ones. Provide them with a few resources for thinking – and feeling – their way through a difficult topic. Beginning this conversation may deepen the bond between you and your patient.

Patients may need or want ideas about how to talk with their families and loved ones about end-of-life care. For some, the prospect of talking with loved ones and family members who may not understand their choices could be more formidable than the idea of death.

It is easier to address the subject of end of life before illness and loss loom too large. One way to think through some of the issues and to address them with potential caregivers is to use stories and scenarios – from newspapers, movies, literature, the radio, or television – as a springboard for conversation. Films like *Million Dollar Baby*, *The Sea Inside*, *Bringing Out the Dead*, and *Talk to Her* are now available from video rental stores and libraries. These films open up end-of-life issues for discussion. Talking about these issues in terms of characters from a film or a story may make people more comfortable than speaking directly about themselves. Ongoing news stories, such as that of Terri Schiavo, also provide occasions for broaching the difficult subject of dying.

The Schiavo case created unprecedented popular interest in end-of-life issues, and thousands of individuals have already responded by preparing advance directives and appointing health care proxies. Nurses and physicians can take advantage of this interest by

making themselves available to patients to answer questions about end-of-life care. Aging with Dignity (www.agingwithdignity.org) provides a document called "The Five Wishes," which guides individuals in making choices about living wills and health care proxies. (This document is available in Spanish as well as English.) A web site devoted to a PBS program, Bill Moyers' *On Our Own Terms* (www.pbs.org/wnet/onourown-terms), offers a wide range of resources for learning and for starting discussions about death. University Hospital makes New York's health care proxy form widely available to patients and families.

Since it will take patients and their loved ones time to process their feelings as well as thoughts about dying, it makes sense to start this discussion now.

—Rebecca Garden



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