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FROM THE GUEST EDITOR

## Shattering the consensus on end-of-life care: Was the Schiavo case palliative medicine's Humpty Dumpty?

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In October of 2005, a two-day conference, “Controversies in End-of-Life Care: Terri Schiavo’s Lessons,” was jointly sponsored by Baystate Medical Center and the Smith College School for Social Work. Both the conference and this special issue of the journal are prompted by recognition that the Schiavo case has clearly generated considerable national attention, and it consequently offers palliative medicine, social work, psychiatry, neurology, and allied disciplines a singular opportunity to reflect on our clinical practices and assumptions about the management of catastrophically ill individuals. At the core of the Schiavo case was a bitter family feud, but before it ended, it became a legal battle, a political fight, a disability rights issue, and a macabre media circus. It is heartbreaking that Congress held a midnight session about the health care of one irreparably brain-damaged woman, Terri Schiavo, while ignoring the health crisis of 40 million uninsured Americans (Friedman, 2005).

The presenters at the conference were instructed to go beyond the sound bites that informed most of us about this complex case, and, instead, to focus in a respectful and scholarly manner on the controversial medical, ethical, legal, social, and psychological issues that it raises. They were urged to sift through the facts and inaccuracies of the case (Hook & Mueller, 2005) and to derive practical lessons. We are simply delighted to provide the journal’s readership with some of the incisive perspectives and observations of the conference’s speakers. As will

quickly become apparent, the authors not only bring to the subject their differing expertise, but also their differing personal opinions and loyalties. We sincerely hope that you find the information provided to be of immediate value to your clinical practices.

The case of Terri Schiavo taps into an ancient ethical debate that goes to the heart of modern end-of-life care (Battin, 2005). On one side is the theistic point of view that it is a mortal sin to attempt to take control over the manner of one’s death. The theists would maintain that this power or privilege belongs only to the Creator. We are living in a world and a country that is increasingly turning to religion for guidance on how to govern our actions. Terri Schiavo’s parents, the Schindler family, clearly embraced the assistance of spiritual counselors (quasi-Franciscan monks), pro-life activists, and religious conservative politicians to enunciate their own beliefs and preferences.

At the Baystate and Smith conference, an evangelical Christian speaker said that those who favored denying Terri Schiavo artificial nutrition and hydration accepted the premise “there is such a thing as a meaningless life.” He was not the only person to utter the word *murder* in connection with this case (Wilson, 2005). We worry that such allegations and accusations may be a major risk management issue that complicates the practice of palliative medicine (Cohen et al., 2005).

On the other side of the great divide is Terri Schiavo’s husband, Michael Schiavo, who is representative of Seneca and the Stoic view that how well one lives and not how long one lives is what really matters. In many ways, Michael Schiavo, who trained to become a nurse to better care for his wife, is also the voice of the prevailing philosophy

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underlying palliative medicine. However, that philosophy was almost overwhelmed by the legislative decisions punctuating the case, and we would strongly suggest that palliative care needs to become more sensitive to the theistic beliefs. Also, although the Stoic position was upheld consistently by the judicial decisions throughout the long course of the case, the recent appointments to the Supreme Court may radically alter future rulings.

Complicating matters is the reality that Western religions differ in their precepts. For example, Orthodox Judaism is opposed to the termination of life support, and one would be hard pressed to discover dialysis being discontinued or ventilators removed in Israeli hospitals. On the other hand, at the conference during a religious panel, the minister from the Haydenville Congregational Church asked, "What does it mean to be human?" Upon reflection, she concluded that a core factor was, "the ability to be in relationship . . . to interact, to be in dialogue with others." By this definition, Terri Schiavo's persistent vegetative state deprived her of the most basic element of personhood.

Even within a single religion, such as Catholicism, there may be differing opinions. **John J. Paris, SJ**, is a celebrated theologian, the Walsh Professor of Bioethics at Boston College, and has served as consultant to the President's Commission for the Study of Ethics in Medicine. His article lucidly explains the current position of the Roman Catholic Church. Father Paris describes a 450-year tradition in Catholic moral teaching regarding the measures by which one should preserve life, and he discusses how this is not altered or appreciably revised by Pope John Paul II's allocution advocating continued provision of hydration and nutrition for the terminally ill. Father Paris is clear that although the Catholic Church has always upheld the sanctity of life, this should not be interpreted to mean the preservation of life at all costs. Striding through the auditorium during the conference, Father Paris asked, "Just what is it we should do with this poor defenseless person we can't cure?" In his article he answers that, "if there are no further physical or spiritual benefit to be gained in sustaining the life, there is no obligation to utilize measures to do so."

**Professor Joan Berzoff** directs the Post-Masters End-of-Life Certificate Program and is the Chair of the Doctoral Program at the Smith College School for Social Work. She is the coeditor of the first social work textbook to address terminal care, *Living with Dying: A Handbook for End of Life Practitioners*, and she assisted in organizing the conference. Her article cogently and sensitively portrays grief and mourning through a psychodynamic

lens. Rather than focus on the pain and pathological consequences of death, attention is directly paid to the constructive ways that mourners grieve. Dr. Berzoff emphasizes that social activism can be a sequellae of death for the survivors, and she alerts us to some of the recent activities of the Schindler and Schiavo families. Among these has been the announcement in December by Michael Schiavo that he was forming a political action committee, and "will do everything in my power to keep another unsuspecting American family from reliving our private national nightmare" (Retaliation in Right-to-Die Case, 2005).

**Judith Kennedy Schwarz, RN, PhD** is the Patient Support Coordinator for Compassion and Choices of New York, an affiliate of the national Compassion and Choices organization, and **Nessa Coyle, NP, PhD, FAAN**, is a member of the Pain and Palliative Care Service at Memorial Sloan-Kettering Cancer Center in New York City, and is the coeditor of the leading nursing palliative medicine textbook. Drs. Schwarz and Coyle have tackled a sensitive and recurring source of conflict in the delivery of palliative care—how should we interpret patients' communications that they wish to die? In particular, they ask whether we can know what Terri Schiavo would have wanted.

In their discussion of advance directives, Drs. Schwarz and Coyle touch on the demographic changes in the United States, and they suggest that there is an increasing likelihood that physicians and other medical staff will care for patients from cultural and socioeconomic backgrounds other than their own (Barker, 1992). However, certain values and social expectations are so ingrained in clinicians as to be unquestioned and yet may also be absolutely alien concepts to patients from different backgrounds (Crawley et al., 2002). Although rudimentary strategies exist, they need to be further developed and incorporated into regular practice.

In her article, **Dr. Linda Ganzini** tackles the thorny issue of withdrawal of artificial nutrition and hydration (ANH) at the end of life. Dr. Ganzini is a consummate researcher, who is best known for the scientific rigor with which she has examined the Oregon Death with Dignity Act. Dr. Ganzini is a Professor of Psychiatry and Medicine at Oregon Health & Science University and a Senior Scholar at their Center on Ethics in Healthcare.

Many people insist that in much the same way as pain management, shelter, and basic personal care are provided, ANH should always be provided (Casarett et al., 2005). According to this position, the removal of ANH results in *starvation*, and this emotionally charged word was also frequently heard in Terri Schiavo's case. The contrary view entails three

key points. First, unlike the provision of food, ANH is a medical therapy that cannot be administered by anyone. Second, the purpose of ANH is not to increase patient comfort, as the sensations of hunger and thirst either abate on their own or with the provision of reasonable palliative care. Finally, unlike shelter or other basic needs, ANH is a procedure that is associated with discomforts, risks, and uncertain benefits. Research has demonstrated that long-term use of percutaneous endoscopic gastrostomy (PEG) leads to complications in 11% of patients, including bowel perforation and peritonitis (Rabeneck et al., 1996; McMahon et al., 2005).

Dr. Ganzini's article adds to our knowledge by not only reviewing the ethical aspects of decision making, but also by describing the evidence for palliative or life-sustaining benefits of ANH in three disease processes: amyotrophic lateral sclerosis, cancer, and dementia. Dr. Ganzini finds that especially when it comes to the last category, current information does not show that PEG either prolongs life or increases comfort in patients with advanced dementia in nursing homes. This has tremendous implications for hundreds of thousands of individuals. Dr. Ganzini concludes that ANH clearly prolonged Mrs. Schiavo's life with no obvious impact on the quality of her life.

Law professors **Zita Lazzarini**, the Director of the Division of Medical Humanities, Health Law and Ethics at the University of Connecticut Health Center, and **Stephen Arons** from the Legal Studies Department of the University of Massachusetts are joined by their student, **Alice Wisniewski**, in the ambitious task of deriving legal and policy implications from Terri Schiavo's case. In their article, they explore the individual patient's right to refuse, withdraw, or insist upon medical treatment where there is conflict over these issues. Conflicts are not limited to those occurring between family members, but also may involve health care personnel or institutions, legal requirements, or third parties concerned with public policy. The authors conclude that protecting and enhancing the privacy of end-of-life care decisions is essential to the very idea of individual liberty in a constitutional democracy, and they contemplate whether there is a basic legal right to palliative care.

**Dr. Benjamin Liptzin** is Chairman of the Department of Psychiatry at Baystate, a Professor at Tufts University School of Medicine, and a geriatric psychiatrist with a special academic interest in delirium. Dr. Liptzin's enthusiasm and support were essential ingredients in the success of the conference. His article approaches the Terri Schiavo case as having highlighted questions about who should be the decision maker when a patient is no longer

competent to decide for him/herself. However, Dr. Liptzin also raises for us the question as to how we would have reacted to this case if Mrs. Schiavo was an octogenarian and not an attractive 26-year-old when she fell unconscious in her apartment in St. Petersburg, Florida. Tapping into his wealth of experience with the geriatric population, he describes the great heterogeneity among older persons and the issues of aging and end-of-life care decisions.

**Dr. Thomas Szasz** is a Professor of Psychiatry Emeritus at the State University of New York Upstate Medical University in Syracuse, New York. He is widely recognized as being a radical and innovative theoretician, and the world's foremost critic of psychiatric coercion. Dr. Szasz is the author of 30 books, among them the classic, *The Myth of Mental Illness*. He has received many awards for his defense of individual liberty and responsibility, and this year was the subject of a new book, *Szasz under Fire: The Psychiatric Abolitionist Faces His Critics*. Dr. Szasz has never been afraid to articulate a powerful challenge, and in this article he states, "Let us call a spade a spade. Terri Schiavo was killed: To be precise she was executed, in accordance with a legally valid court order, by starvation and dehydration."

It is probably a reasonable assumption that most readers of this journal share the position of Terri Schiavo's husband, Michael. Accordingly, it is a particular delight for us to provide Dr. Szasz's intellectually stimulating and far-ranging article that unambivalently takes the side of the Schindler family. Among the points that he makes is, "Most people who are not religious prefer to be completely dead rather than half dead. They usually assume that their closest relatives, the persons who truly deserve the awkward appellation "loved ones," share this choice."

**Dr. Joseph Fins** is a practicing internist at New York Presbyterian-Weill Cornell Medical Center, where he chairs the hospital's ethics committee and is the author of over 150 publications in medical ethics and health policy. He has also recently published *A Palliative Ethic of Care: Clinical Wisdom at Life's End*. In his article he further articulates "a palliative neuroethics of care for those touched by severe brain injury and disorders of consciousness." Dr. Fins examines what he labels as being the fragile consensus underlying end-of-life care. He also discusses the famous videotape of Terri Schiavo in her hospital bed, and he instructs us on the criteria for diagnosing a permanent vegetative state and other modern disorders of consciousness.

This last has proven to be of more than mere academic interest to the staff of Baystate Medical Center. We are presently agonizing over a case

involving an 11-year-old child, Haleigh Poutre, whose treatment began in the Pediatric Intensive Care Unit and has continued at the Franciscan Hospital for Children in Brighton (Belluck, 2005). Haleigh's injuries followed abuse at the hands of her adoptive parents, the most serious of which was a partly sheared brain stem. Initially diagnosed as having a "persistent" (not "permanent" like Terri Schiavo) vegetative state, her recent improvement is now reported as being more consistent with that of a minimally conscious state. This is carefully defined by Dr. Fins as being a state of severely altered consciousness in which there is minimal but definite behavioral evidence of self or environmental awareness and which carries the potential for additional recovery (Schiff, 2005).

In reference to the Baystate case, some commentators are describing a post-Schiavo syndrome, characterized by an unwillingness to once again publicly pontificate over the implications of similar tragedies. Frankly, we hope there is such a phenomenon, and that the field of medicine is permitted additional time to quietly absorb and digest the lessons of Terri Schiavo. We hope that this special issue of the journal provides you with just such an opportunity to mull over the observations and conclusions of a remarkable group of thinkers. Finally, we also believe that this is one Humpty Dumpty that can be reconstructed better than the original.

## REFERENCES

- Barker, J.C. (1992). Cultural diversity—Changing the context of medical practice. *Western Journal of Medicine*, 157, 248–254.
- Battin, M.P. (2005). *Ending Life: Ethics and the Way We Die*. New York: Oxford University Press.
- Belluck, P. (2005). Girl's end-of-life case questions a difficult decision and who is fit to make it. *The New York Times*, December 6, A18.
- Casarett, C., Kapo, J., & Caplan, A. (2005). Appropriate use of artificial nutrition and hydration—Fundamental principles and recommendations. *New England Journal of Medicine*, 353, 2607–2612.
- Cohen, L.M., Ganzini, L., Mitchell, C., et al. (2005). Accusations of murder and euthanasia in end-of-life care. *Journal of Palliative Medicine*, 8, 1096–1104.
- Crawley, L.M., Marchall, P.A., Lo, B., et al. (2002). Strategies for culturally effective end-of-life care. *Annals of Internal Medicine*, 136, 673–679.
- Friedman, T. (2005). Singapore and Katrina. *New York Times*, September 14. Available at: <http://www.nytimes.com/2005/09/14/opinion/14friedman.html?hp>.
- Hook, C.C. & Mueller, P.S. (2005). The Terri Schiavo saga: The making of a tragedy and lessons learned. *Mayo Clinic Proceedings*, 80, 1449–1460.
- McMahon, M.M., Hurley, D.L., Kanath, P.S., et al. (2005). Medical and ethical aspects of long-term enteral tube feeding. *Mayo Clinic Proceedings*, 80, 1461–1476.
- Rabeneck, L., Wray, N.P., & Petersen, N.J. (1996). Long-term outcomes of patients receiving percutaneous endoscopic gastrostomy tubes. *Journal of General Internal Medicine*, 11, 287–293.
- Retaliation in Right-to-Die Case. (2005). *The New York Times*, December 9, A27.
- Schiff, N.D. (2005). Modeling the minimally conscious state: Measurement of brain function and therapeutic possibilities. *Progress in Brain Research*, 150, 473–493.
- Wilson, S. (2005). Matters of life and death: Smith College conference ponders lessons learned from the Terri Schiavo tragedy. *Daily Hampshire Gazette*, October 18, C1–C2.