What Can Anthropology Contribute to the Terri Schiavo Debate?

By Barbara Koenig, PhD

For weeks last year each time I turned on my car radio the national news opened with an assessment of Schiavo’s condition, or a description of battles among family factions, or an update on the latest legal appeal to prevent her death from “starvation.” Op-ed pages carried in-depth historical discussions of America’s right-to-die movement, offering advice on how to update one’s living will. The claims of Schiavo’s husband were consistent with what most people in the oft-quoted bioethics community consider settled legal territory: those who express their prior wishes to die without technological interventions should be allowed to do so. A feeding tube can be disconnected like any other piece of machinery.

But is it that simple? What caused the intense political maelstrom, the challenge to a seemingly settled public consensus? And what can anthropology contribute to this ongoing debate, a dialogue historically influenced by legal scholars focused on individual rights and bioethicists advocating patient autonomy.

I have spent almost three decades ethnographically studying the problem of death in contemporary US biomedicine, leading me to question the assumption...
that death can be managed through the exercise of rationally-made choices documented in legally-sanctioned advance care directives.

**Between Life and Death**

Consider the following claim: The boundary between life and death is socially created; it cannot be easily ascertained or “read,” even by the most sophisticated brain imaging technology. Anthropologists are unlikely to contest such a claim. Others expect a bedrock of certainty, informed either by religious faith or science.

**Is a patient diagnosed** as in a “persistent vegetative state” (PVS) meaningfully alive? The vehemence of the public debate—with conservative commentators describing Schiavo’s “execution” by a liberal, out-of-control judiciary suggests a high degree of conceptual confusion. Although parts of her brain had been seriously damaged, Schiavo’s body clearly lived on. Even people legally declared brain dead appear closer to sleep than death, as Margaret Lock’s compelling ethnographic treatment of the topic, *Twice Dead*, reveals.

**What the Schiavo debate** failed to reflect is a distinction between “being alive” and the more complex dimensions of social personhood recognized in anthropological accounts. Under the narrow legal view, all that mattered was her prior proclamation of a “right to die” when in a state of cognitive decline. Yet social personhood need not be defined by biological life.

**There is an interesting paradox.** Not mentioned in the discussion of Schiavo’s diagnosis (PVS) is the fact that many in the organ transplant community—especially those interested in correcting the national organ shortage—have suggested the use of PVS patients as appropriate organ donors, given their prior consent to donate organs should their cognitive functions fail. Imagine the legal battles that might ensue when a family disputes one member’s choice (documented carefully in writing) to donate vital organs rather than continue in PVS. Current practice within the transplant community tends to refrain from harvesting organs from the brain dead when relatives object, even though legal rules may allow it. The *uber* individualism of American rights practices gives way to the reality of social connectedness.

**Cryonics** is the most extreme boundary clash. Advocates of freezing corpses (or brains) for later reanimation simply redefine their subject’s bodies. As noted by Steve Bridge, founder of the Alcor Life Extension Foundation, “We don’t believe we’re freezing dead people and that someday there will be a miracle and dead people will come back to life. What we think we’re doing is freezing people who are incorrectly labeled as dead by the medical technology of today.”

**Anthropologists will recognize** the cultural theme—striving for immortality—now manifest in technological language, goals and assumptions. Stay tuned for the next battle, which will be fought at the nexus of biomedical commerce, human embryonic stem cells and genomic technologies. Selling immortality is a proven commercial winner, as promised by pioneering scientist William Haseltine, who told a biotech conference, “The fountain of youth is likely to be found within our own genes.” Will we soon be making living wills where the check-off boxes include preferences for 1) body freezing, 2) organ donation prior to death, or 3) indefinite prolongation of bodily functions.

**Dying and the Rhetoric of Choice**

My own work locates the hub of the problem in the rhetoric of “choice” embraced by most advocates of end-of-life reform. I’ve argued that living wills and legal documents like the durable power of attorney for health care have been oversold as the key to reform. All of us, so the argument goes, should simply write down our end-of-life care desires upon reaching the age of 18. Ethnographic studies reveal how the assumptions behind these bioethics practices simply do not hold up. There is resistance on the part of doctors and patients alike. At the height of the Schiavo crisis a Florida reporter asked what I thought would be the legacy of the case in ten years. I answered that my greatest fear is that the main public message flowing from the controversy will be a renewed call for the widespread use of advance directives specifying a surrogate decision maker or an expanded use of living wills. (Indeed, this has happened.)

**A range of empirical studies** of advance directives and living wills have consistently documented my own findings that such practices are a well intentioned but failed project in public policy. Well intentioned because based on the highest ideals of respect for individual autonomy, but deeply flawed because of incorrect assumptions about the way people make decisions and of how the health care system is structured. We are not rational calculators balancing length of life against a metric of suffering as though making a choice about mortgage rates or the purchase of a new computer.
I imagine that many of my colleagues will take issue with these comments, claiming a strong personal desire for choice and control over their own dying. And indeed, like many Americans I did use the Schiavo case as an opportunity to update my own “living will.” But not because I believe in such documents, rather because I pragmatically accept that such instruments are necessary given the failings of the health care system in managing death; and those failings are grave. The defaults built into the current system preclude good care.

My own document is constructed in the form of a letter to my physician. One reason for that format is that my research experience tells me that making family members complicit in decisions to withhold treatment often leads to paralysis. The task of end-of-life decision-making is staggeringly complex, requiring a level and sophistication of communication that is rarely met. With a colleague I wrote a paper titled, “Speaking Around Death.” Based on linguistic recording and observation of decisions about hospice referrals, the key finding is that patients and families simply don’t get the message physicians think they are conveying. The fundamental assumptions undergirding the choice model are not met.

Policies that require patients to embrace their death in order to receive end-of-life care are another awkwardness in the current system. The notion of choice makes sense within a consumer society dominated by markets. Imagine a battle of direct-to-consumer ads, one promises a cure for your cancer, the second a good death. The former exist; I’ve assembled a large collection of such ads. They invite the health consumer to select a particular cancer center or even a specific procedure. The latter speak through their absence. Unlike services that purport to extend or save life, end-of-life care is most often a source of costs rather than revenue for hospitals, and advertising a good death conflicts with the bottom line.

**Issues of Health Equity**

Anthropologists, more than other scholars, are likely to draw connections between first-world practices and issues of health equity—both locally and globally. In the developed world the “life” of almost any individual body can be extended, the dying process prolonged. But consider the resources expended to maintain Schiavo’s bodily functioning for 15 years magnified by millions. Picture Terri Schiavo’s white body cared for by the labor of many black and brown bodies, people who themselves lack health insurance. Given increasing US income disparities this gloomy image is becoming thinkable. In his recent book, *Pathologies of Power*, physician-anthropologist Paul Farmer reflected on the contrasting deliberations about technologies that stave off death in his two clinical homes, rural Haiti versus a Harvard teaching hospital. In Haiti he is frantic to apply technologies known to work and save lives, such as antibiotics. On Harvard “ethics rounds” discussions focus on when to forego medical technologies likely to be futile.

So the tools of anthropology are critical for making sense of the Schiavo uproar, both for understanding its full complexity and for guiding policy solutions that are fair, just, and account for cultural resistance to choosing how we are to die. Managing our mortality against the backdrop of technological claims to life everlasting is the hardest problem facing contemporary American biomedicine. Wielding only the weapon of individual choice will inevitably lead to failure.

**Advance care directives**, an unsuccessful social project, will not be enough, in spite of revived attention at this post-Schiavo moment. I predict that as time passes interest will fade and resistance will re-emerge. Likewise, ignoring the social forces determining who is considered “dead enough” to provide organs or to go without a feeding tube will only increase the conservative backlash against the “culture of death” agenda that contemporary bioethics, along with judges and the liberal left, stands accused of.

All human societies confront mortality. To improve how we die, we must first understand how our health care system fashioned death its mortal enemy while embracing immortality through technology as a goal, and how this strange cultural assemblage is maintained.
The crisis of the HIV epidemic in San Francisco led Koenig, like many anthropologists, into AIDS work. While still completing her thesis Koenig joined the UCSF faculty, remaining until 1992 when she was recruited to build the bioethics research program at Stanford. Throughout the 1990s Koenig worked with clinicians to consider how the new bioethics clinical practices governing end-of-life care affected culturally-diverse patients. Autonomy-based innovations seemed to fall flat, but why? Her first NIH-funded research examined these issues, leading to Koenig being named a “Faculty Scholar” by the Open Society Institute’s Project on Death in America.

At Stanford Koenig developed research programs that complemented the university’s scientific strengths, including a program in “Genomics, Ethics and Society,” which examined new genetic tests, “race” and human genetic variation research, and the onset of individualized medicine.

Koenig was a founding member of several clinical ethics committees and has experience with IRBs and data safety monitoring boards. Her national service included the Clinton administration’s “Secretary’s Advisory Committee on Genetic Testing,” a body charged with making recommendations about the introduction of new tests into clinical practice. Currently she serves on a committee that provides ethics counsel to the director of the Centers for Disease Control (CDC).

Examining the ethical trajectory of emerging biomedical technologies remains Koenig’s primary research focus. She continues to divide her thinking and writing time between end-of-life care and genomics. Her current NIDA-funded research is titled “The Genetics of Nicotine Addiction: Examining Ethics and Policy.”

At Mayo, Koenig’s goal is to build an active, interdisciplinary bioethics research program, one that includes strong links with faculty and students at the University of Minnesota Center for Bioethics.

Selected Publications of Barbara Koenig

REPORTS

BOOKS

BOOK CHAPTERS


ARTICLES


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**Center News**

**Dianne Bartels**, RN, MA, PhD, has been appointed a consultant to the National Society of Genetics Counselors Ethics Committee.

**Ronald Cranford**, MD, has been selected as the 2005 recipient of the Shotwell Award by the Hennepin Medical Society of Minneapolis. The Shotwell Award is presented annually to a person in the State of Minnesota for noteworthy efforts in health care.

**Carl Elliott**, MD, PhD, has been appointed to the Editorial Board for *BioSocieties*, Cambridge University Press and London School of Economics.

**Carl Elliott**, MD, PhD, was awarded grants from the NIH-NLM Grant for Scholarly Workings in Biomedicine and Health; and from the University of Minnesota Graduate School for research on ethics and pharmaceutical marketing.

**Jeffrey Kahn**, PhD, MPH, co-investigator and John Riedl, PhD, Principal Investigator were awarded an NSF grant for a project on Helping Hands: Computer Support for Community Based Maintained Artifacts of Lasting Value.

**Steven Miles**, MD, has been awarded the University of Minnesota Alumni International Distinguished Physician Award.

The Center welcomes international visitors **Ting Liu** and **Mengmeng Zhou**, students from Peking University Health Science Center, Beijing, China. Both students are visiting the Center in spring semester. Ting Liu’s focus is on ethical theory and bioethics and Mengmeng Zhou will focus on ethics and research on human subjects.
Osher Lifelong Learning Institute Bioethics Series

March 22 – May 10

Center for Bioethics faculty will participate in the eight week lecture series sponsored by the Osher Lifelong Learning Institute, University of Minnesota. The series will be held on the University of Minnesota campus and will address current issues in bioethics. For more information, call 612-624-7847.

March 22
“Your Doctor Gets Paid for What?! The Ethics of Pay for Performance Modes of Physician Reimbursement,” by David Satin, MD.

March 29
“End of Life—Terri Schiavo,” by Dianne Bartels, RN, MA, PhD.

April 5
“The Ethics and Politics of Stem Cell Research” by Carol Tauer, PhD.

April 12
“Title to be announced” by John Song, MD.

April 19
“Dentists Who Care: Inspiring Stories of Professional Commitment,” by Muriel Bebeau, PhD.

April 26
“Title to be announced” by Carl Elliott, MD, PhD.

May 3
“Human Embryos, Stem Cells, and other Ethical Issues,” by Jeffrey Kahn, PhD, MPH.

May 10
“Title to be announced” by Steven Miles, MD.

Recent Faculty Publications

Book Chapters

Articles


Annual Bioethics Seminar Series

*Continuing Medical Education (CME) credit available*

Center seminars have been designated to meet University of Minnesota continuing medical education requirements and provides 1 contact hour in continuing education (.1 CME) for each seminar. Registration is required if you are attending for CME credit.

Seminars are held from 12:15–1:30 pm in 2-122 Molecular & Cellular Biology building (MCB) on the University of Minnesota campus. Previous seminars may also be accessed on our website in BREEZE format see www.bioethics.umn.edu.

MAR 24 “Pharma Goes to the Laundry” by Carl Elliott, MD, PhD, Center for Bioethics, University of Minnesota.

APR 21 “Human Mistakes and Mishaps: Disability, Children, and Atavism” by Amy Laura Hall, MDiv, PhD, Duke University Divinity School.

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MAY 10 “Title to be announced” by Steven Miles, MD.
Calendar of Events

Mar 22
Jeffrey Kahn, PhD, MPH, will speak at Keio University, Tokyo, Japan. For information, call 612-624-9440.

Mar 28
Dianne Bartels, RN, MA, PhD, will speak on “End of Life Care after Terry Schiavo” at the Minneapolis American Association of University Women, (AAUW), Minneapolis, MN. For information, call 612-624-9440.

Apr 6
Jeffrey Kahn, PhD, MPH, will speak on “Ethics of Stem Cell Research” at the American Academy of Audiology Symposium, Minneapolis, MN. For information, email lyonkers@audiology.org.

Apr 7

Apr 9
Carl Elliott, MD, PhD, will speak on “The Limits of Disclosure,” Conference on “Ethics and the Business of Biomedicine,” University of Tennessee, Knoxville, TN. For information, email denisarnold@comcast.net.

Apr 12-18
Muriel Bebeau, PhD, will present a paper “Renewing a Sense of Professionalism Following Disciplinary Action” at the Annual Meeting of the American Educational Research Association, San Francisco, CA. For information, call 612-625-5138.

Apr 21
Jeffrey Kahn, PhD, MPH, will participate in a roundtable discussion “Moving Forward in Food Protection and Defense” at the University of Minnesota’s Consortium on Law and Values in Health, Environment & the Life Sciences Annual Conference, Minneapolis, MN. For information, visit www.lifesci.consortium.umn.edu/conferences/.

Apr 26
Jeffrey Kahn, PhD, MPH, will speak on “Bioethics: Past, Present and Future” at the College of St. Scholastica’s Minnesota Dialogue, Duluth, MN. For information, email president@css.edu.

May 1
Jeffrey Kahn, PhD, MPH, will speak at the 15th Annual Max and Rose Sadoff Memorial Symposium on Pharmacy, Law and Ethics, Minneapolis, MN. For information, call 612-624-1900.

May 9
Maryam Valapour, MD, will speak on “Ethical Issues in Organ Transplantation” at the LifeTrac Network Conference, Minneapolis, MN. For information, call 612-624-9440.

June 1
Jeffrey Kahn, PhD, MPH, will speak on “Accountability and Leading Edge Biotechnology: The Ethics of Creating Stem Cell Donors” at the University of Colorado Health Sciences Center, Denver, CO. For information, email john.moorhead@uchsc.edu.

June 11–16
Jeffrey Kahn, PhD, MPH, will speak on “Ethical Issues in Emerging Technologies” and “A Model for Implementing Training in Ethics” at the University of Pittsburgh’s Survival Skills & Ethics Program 11th Annual Trainer-of-Trainers Conference, Snowmass, CO. For information, visit www.survival.pitt.edu/events/trainer.asp.

Visit our website at www.bioethics.umn.edu for bioethics courses offered in Fall 2006. The website also includes information on other educational opportunities, events, faculty descriptions and research, overviews on topics in bioethics, and many other resources.
Center Faculty & Staff

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The Spring session will include new topics. Dates are Mondays—May 8 and 22; and Tuesday, May 16 from 6–8 pm on the University of Minnesota campus. On-line registration is available at www.ahc.umn.edu/outreach/minimed/.