MEDICAL HUMANITIES REPORT

Reflections on Schiavo: Are medicine, ethics, and law enough anymore?

by Gerald S. Schatz
Center for Ethics and Humanities in the Life Sciences

What does the long, sad, bitter controversy concerning Theresa Schiavo now imply for medicine, medical ethics, law, patients, and caregivers? Neither her medical condition nor the siege litigation over whether her artificial hydration and nutrition should be discontinued had presented novel issues of medicine, bioethics, or law. Florida's courts screened evidence for credibility and relevance concerning her neurological status, her wishes, her best interests, the fitness and conduct of her husband, Michael Schiavo, as her guardian, and how these several factors came together in determining whether her artificial nutrition and hydration could be ethically, legally discontinued.

In proceedings reviewed through multiple appeals, the courts concluded that she was in a persistent vegetative state with no reasonable medical hope of recovery. They sustained her husband's guardianship and permitted him to have artificial nutrition and hydration withdrawn. The failure of legislative and executive branch challenges rested on conventional law. Even now, Schiavo presents nothing new in medicine, medical ethics, or law except this: An intimidating legislative and executive branch willingness to presume about the individual patient and the medicine, to decide upon the ethics, and to demand and steer subsequent proceedings seemingly indefinitely.

I do not disparage the view that persons in what the courts found to be Theresa Schiavo's position should not have their artificial nutrition and hydration withdrawn absent their prior expressed wishes to the contrary. Nor do I disparage concern for Theresa Schiavo or for revisiting what the law should be. I do not know the medical or other legally relevant personal facts other than those that Florida's courts, the only ostensibly neutral evaluators, found credibly inferable. So I am not qualified to say what the outcome should have been for Theresa Schiavo. I am concerned about how we decide.

My dismay is with the attempts to set constitutional law aside, and I worry about the implications for medical care. The wrenching ethical problems of caregivers in trying to decide what is right and medically appropriate for this patient, the great difficulties of courts in trying to ascertain what is believable and what is fair, and the subjection of all of this to prolonged and painful judicial review, which is how our society has set itself up to deal which such conflicts, would have seemed to be enough. Notwithstanding the law or the established medical facts, the Florida Legislature tried to disregard a case that had been pursued to legal finality and to invest the governor with judicial prerogatives but no criteria for decision. When that failed in the Florida Supreme Court and the U.S. Supreme Court refused review, the Congress sought to set aside the actions of the Florida courts. When that failed, Florida's governor tried to get state custody of Theresa Schiavo and was reminded in court that the case had already been decided.

Florida's Legislature and governor and Congress and the President showed that at least in a bioethics matter a settled judicial outcome not to their liking could incur yet further costs in time, litigation, and unhappiness. Many guardians, caregivers, hospitals, hospices, and house counsel may be especially wary in these matters henceforth, which is not all to the bad. But they are likely to be inappropriately wary, regardless of the ethics and the law, because they have seen legislative power applied with impunity in attempts to thwart the law. They may discourage or delay those ethical decisions that might trigger direct legislative or executive branch interference. We may have made our medical directives or otherwise credibly declared our medical preferences, and we may have our medical proxies, empowered by ourselves or by operation of law, and the courts may uphold our preferences and proxies through numerous reviews. But if our legislatures and executive branch officials dislike the diagnosis, prognosis, or likely outcome, then one possibility now vivid is a legislative and executive legal siege.

The Schiavo controversy was not the first such dispute. It happened in Virginia with the case of Hugh Finn, whose wife successfully fought off a legislative intrusion. That was an expensive fight, and Schiavo more so. It is easy enough to imagine the emotional burden on all parties. Add in the inchoate but terribly important burden on the patient's own dignity. Through events not of their making, Hugh Finn and Theresa Schiavo had become symbols, or perhaps tokens, in lieu of personhood.

For these reasons, for me the most significant ethical statement arising from all this is the Florida Supreme Court opinion that declared the legislative override an unconstitutional violation of separation of powers. The Legislature had tried to overrule a final court decision and it had tried to vest judicial powers in the governor without standards for decision. The Florida Supreme Court's decision was not about Theresa Schiavo, although surely it would affect her; it was about governing. That court ruled:

> The continuing vitality of our system of separation of powers precludes the other two branches from nullifying the judicial branch's final orders. If the Legislature with the assent of the Governor can do what was attempted here, the judicial branch would be subordinated to the final directive of the other branches. Also subordinated would be the rights of individuals, including the well-established privacy right to self-determination. No court judgment could ever be considered truly final and no constitutional right truly secure, because the precedent of this case would hold to the contrary. Vested rights could be stripped away based on popular clamor. The essential core of what the Founding Fathers sought to change from their experience with English rule would be lost, especially their belief that our courts exist precisely to preserve the rights of individuals, even when doing so is contrary to popular will.
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> The trial court's decision regarding Theresa Schiavo was made in accordance with the procedures and protections set forth by the judicial branch and in accordance with the statutes passed by the Legislature in effect at that time. That decision is final and the Legislature's attempt to alter that final adjudication is unconstitutional as applied to Theresa Schiavo. Further, even if there had been no final judgment in this case, the Legislature provided the Governor constitutionally inadequate standards for the application of the legislative authority delegated in [the challenged law]. Because [the challenged law] runs afoul of . . . the Florida Constitution in both respects, we affirm the circuit court's final summary judgment.

As noted, the U.S. Supreme Court declined to review that decision. Courts can make evidentiary, procedural, and legal mistakes. So there are appellate reviews. The law itself may be wrong. These are appropriate issues for public concern. The applicable law might need changing. There may be justification for correcting palpable injustice. Skirting constitutional principles and

putting legislatures and governors in charge of bedside decisions is a dubious prospect. However motivated, it is not medicine, ethics, law, or law reform; it is deciding tragic, individual cases by clamor.

MEDICAL HUMANITIES REPORT

Complementary and Alternative Medicine

by Judith Andre
Center for Ethics and Humanities in the Life Sciences

Once, in the United States, it was simply called "alternative medicine." (The more welcoming "complementary" seems to have originated in England, where it was in use in the 1980s; ten years later it reached the United States. Today both countries usually use the longer phrase, "complementary and alternative medicine," or CAM.). The phrase "alternative medicine" prompted a famous jab, often attributed to Marcia Angell: "Alternative to what? Medicines that work?" If that were the case, of course, ethical issues about them would be relatively easy. Patients have a right to use the therapies of their choice, and clinicians have a right not to participate when they believe the therapy is useless or dangerous.

But what "alternative" means in this context is simply different from conventional medicine, from what Western-trained doctors ordinarily use. The quip attributed to Angell suggests that everything used in conventional medicine works, and nothing labeled alternative does, neither of which is true. In fact the opposition-by-definition between "alternative" and conventional medicine has quite different, and philosophically interesting, implications: as soon as anything called "alternative" is taken up widely within conventional medicine, it will lose its status. And since–despite the "evidence-based medicine" movement–conventional practice is still only somewhat responsive to evidence, accepting (or appropriating) CAM might be done for reasons other than evidence of efficacy.

Whatever she may have said a decade ago, today, at least, Angell speaks with much more understanding about the subject (see her Frontline interview.) Most basically, she understands that more is at issue than whether a particular chemical has a physiological effect. She points out that while we have a more powerful armamentarium of drugs (and technology) than ever before, the ways in which they are made available to patients may be worse. Medicine as a system is too often impersonal, overwhelming, and bureaucratic. Research has shown what common sense always suggested: that the nature of the encounter between clinician and patient helps, and hinders, healing. Medical education in the past few decades has been increasingly dedicated to skills in communication, in cross-cultural sensitivity, and so on. But the problems are less with individual clinicians than with the system as a whole, vast, expensive, and inefficient. (Much of the inefficiency results from our struggles to control costs through the private sector, a deep and blind faith that markets are infallibly beneficial.) Our young doctors are often sensitive, humane practitioners, frustrated by the systems in which they must practice. In contrast, many forms of CAM are intrinsically holistic. Massage, for instance, entails time and touch. Prayer and meditation center the person in a quest for meaning. Aromatherapy is hard to quantify ("three sniffs every 20 minutes"?).

So non-chemical factors (e.g., quiet, a sense of safety, a belief that something is efficacious or that someone cares) have physiological consequences. This gives rise to yet another paradox. NIH recently established a National Institute of Complementary and Alternative Medicine (NCCAM), which will use scientific methods to investigate various complementary and

alternative therapies. If some technique now considered CAM were shown to be beneficial and taken up into conventional medicine, it might be so transformed that what makes it effective is lost. (It might, for instance, be administered in a quantified, mechanical, and hurried manner.) Or what makes it appealing might be lost: for some people, prescription drugs carry a stigma, and CAM seems "natural." For others, rejection of convention is part of their identity; they would not be attracted to CAM if it were incorporated into standard medical practice.

CAM, then, can be helpful or dangerous, and we may not know which; it can be used, as Angell suggested, in place of something that is more likely to be effective. The meaning that it carries for patients can be part of what makes it effective.

For these reasons NCCAM might have unexpected consequences. Yet there is no question that much of CAM involves chemically active ingredients, and it is important to know what they do. (The mistaken belief that "natural" means "safe" is common and dangerous.) Howard Brody points out that it is also important to know which of the human elements in a medical encounter contribute to its healing effects. He believes the evidence points toward three elements: caring, a patient's sense of control, and the patient's belief that she and the clinician agree about the nature of the illness. Reliable information about dosage and modes of administration could promote standardization in manufacture and use. As things stand now, many herbals and supplements are not only little researched, they are manufactured in haphazard ways, so that the amount of the claimed ingredient can vary even from pill to pill. Furthermore other ingredients, unmentioned on the label but biologically active, may be present as well.

This background gives rise to complex ethical issues, about what to say to outpatients, and what to allow for inpatients. The conflicting values include patient autonomy, clinician integrity, beneficence and nonmaleficence, and the need of institutions to protect themselves.

On the first question concerns what to say to outpatients: Answer questions? Mention or even encourage CAM? One attractively simple answer is "Don't ask, and don't tell." Those advocating this position remind us that what patients do is their own business, and the clinician's, by definition, is to provide conventional care. Therefore clinicians need not be involved, indeed are safer not being involved, in areas where they have no expertise. To the contrary, however, a clinician dedicated to the patient (rather than to his or her own safety) will need to be aware of, for instance, substances the patient may be ingesting, since they could alter lab findings or interact with prescribed medications... Furthermore, it goes without saying that patient's questions must be answered, and answered honestly. So "don't ask, don't tell" is an indefensible position.

A more complex and responsible set of recommendations suggests the following:

- Honestly answer patients' direct questions about CAM.
- Elicit information about their use of it.
- Establish patients' understanding of what they are using, or considering using (for conventional as well as complementary therapies).
- Clarify patients' goals.
- Reflect on whether to offer information, taking into account the patient's burden of illness, his or her expressed preferences and the risks and benefits of both conventional and complementary therapy.
- Become informed about available CAM that has consistently been shown to be safe and effective; to be ineffective and/or harmful; or about which patients consistently inquire.
- Become familiar with qualified and competent CAM practitioners (medical and non-medical) to whom referrals can be made when necessary.

- Continue a relationship with the patient, while continuing to monitor the patient conventionally and staying open to further discussions about CAM.[1]

These suggestions speak to clinicians as individuals. Institutional policies must address a more complex set of issues. Policy consists of general rules, which can never be perfectly fitted to each situation, and which must balance one set of likely benefits and harms against a different set. In addition, a hospital's obligations include self-protection, since (ordinarily) damage to a hospital amounts to damage to the patients it serves: financial damage takes resources from patient care, reputational damage undermines patient trust, and a hospital's closure often creates great hardship. On the other hand, hospitals are famously and at times unjustifiably risk-averse; policies should be concerned first about helping the particular, real patients they are now serving.

To be specific, then, what should the policy be in regard to CAM brought into a hospital by a patient? One possibility is to require that the pharmacy be asked to identify the substance; if it can, then the information is given to the doctor, and the decision about its use is left to physician and patient. If the pharmacy cannot identify the substance, then it may not be used. It could be argued, however, that even in the case of unidentifiable substances, the decision should be left to physician and patient. It would seem better to require only that pharmacy be asked whether it can identify the substance; that answer is information, which the clinician and patient use to make their decision. Here as everywhere, borderline cases would arise: when is something a "medicine" and therefore subject to the rule? Must herbal teas, or cranberry juice concentrated in a capsule, be sent to pharmacy for its opinion? The earlier question of just what counts as "complementary or alternative" medicine has reappeared, here concerning the boundary not been conventional and alternative, but between food and medication.

Finally, another boundary raises the most challenging questions of all. Suppose it has been established that marijuana is sometimes medically useful, but suppose also that its use is illegal. All the recommendations above, from keeping informed to answering a patient's questions honestly, would certainly apply. But what about caring for an inpatient who has brought her own supply? This is a dilemma I will leave for the reader.

(I am grateful to the Ethics Committee of the Rehabilitation Institute of Michigan for a stimulating discussion of the above issues. Much of bioethics focuses on issues in acute care; rehabilitation medicine must deal with a challengingly different set.)

References

1. Adapted from "Ethical and legal issues at the Interface of complementary and conventional medicine," I.H. Kerridge, J.R. McPhee. *Medical Journal of Australia*. 2004. Aug 2; 11(3):164-6.

MEDICAL HUMANITIES REPORT

InkLinks *is a regular column in which readers reflect on issues related to the previous lead article. In the last issue of* MHR, *Howard Brody asked whether two moral ideals are reconcilable. (The occasion for his article was a workshop we held last June on bioethics and the disabled. Len Fleck's "audience response" system garnered some surprising responses.) The first of the conflicting principles was, roughly, "the frailty of old age is a disability, and it is wrong to discriminate on the basis of disability." The second was, again roughly, "death is inevitable, and at a certain point expensive efforts to prolong life are a misuse of scarce resources." Several readers have responded to Howard's question.*

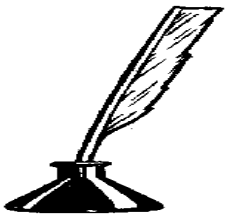
A Philosopher: Defining Disability Too Broadly Misses the Point. We Need to Talk.

Len Fleck, Ph.D.
Center for Ethics and Humanities

The "disability movement" is not a single powerful political force. It is a minimally coordinated array of disability interests, very often competing with one another rather than cooperating. The disability movement has sought to expand its political power by embracing a more inclusive definition of disability, hence the move to include the frailties of old age as disabilities. Still broader expansions have been suggested: When persons with significant heart disease and progressive cancer are included, very large numbers of people are brought under the disabilities umbrella. But that expansion is the equivalent of inviting two 800-pound gorillas into your kitchen and not expecting any broken crockery. Take, for example, a drug like Erbitux, which costs $12,000 per person per month. It doesn't cure; it provides a marginal increase in life expectancy. Cancer care in the US currently consumes about $100 billion per year. Because of drugs like Erbitux that annual cost is likely to be $750 billion by 2015. If there is a political contest for limited health care resources between advocates for persons disabled by cancer and advocates for persons with a range of physical disabilities who need assistive technologies to restore function, which group is likely to "win"?

Instead of that kind of political struggle, it is in the interest of all members of the disability movement that we have a rational public conversation aimed at articulating fair or just health care rationing protocols across the health care spectrum. Allocation and rationing decisions are going to happen whether or not such a conversation occurs. The real practical (and moral) question is whether such decisions will be the result of the exercise of ethically uninhibited political or economic power, or the outcome of a rational social conversation governed by a conception of health care justice we can all endorse as reasonable.

MEDICAL HUMANITIES REPORT



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A Disabilities Advocate-Theorist: Invite the Gorillas in, and Then Let's Talk.

Adrienne Asch, Ph.D.
Wellesley College

I do think it is appropriate to include people with heart disease and cancer in the disability movement, community, etc., and then I think we have to face what the 800-pound gorilla requires when invited into the room. I do think we need a democratic deliberation on health care rationing, and we may have to have difficult conversations about differences between stable and progressive impairments, between levels of impairment, and so on. The principle that at a certain point death should no longer be aggressively postponed is one I can tolerate. Trying to evade the fact that we will all die is the greatest of foolishness and the worst of a pursuit of the consumerism and perfectionism that puts at a disadvantage everyone who cannot meet norms of youth, beauty, strength, and mental agility.

If people with disabilities felt they would get a fair shake at resources, that their impairments would not be used against them, they would have an easier time imagining that perhaps no one should get heart transplants at age 80. But people with disabilities have every reason to oppose using impairment (even profound cognitive impairment, as in late stage Alzheimer's) as a reason to avoid treatment, if the treatment would allow the persons to go on living the lives they were living before. To say that any of those lives, however good or bad they are, is worth less than the life of someone without an impairment is simply discrimination. I am not convinced that we should be creating technologies for some that we will not give to all, regardless of age or impairment.

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A Geriatrician: Let the Elderly Choose for Themselves

Larry Lawhorne, M.D.
Family Practice

The essay on age-based rationing by Howard Brody summarizes very well the debate among bioethicists and advocates for persons with disabilities. These arguments are familiar to those of us in the trenches. But after almost 30 years of nursing home experience, I have come to believe that neither rationing nor the fair and caring distribution of health care resources can be accomplished by crafting public policy incorporating criteria that detail who should or should not receive services. Such criteria will almost certainly be arbitrary because calculated benefits and risks are derived from epidemiologic data that by their nature carry some variability and uncertainty. In addition, the epidemiologically-derived estimates of benefits and risks do not take into account a person's need and ability to complete the "unfinished projects" that Dr. Brody describes.

Preferable is an approach that offers each individual meaningful choice at times of transition– an approach that also acknowledges the ambiguities inherent in these situations. When an older person starts to decline, we ask, "Is this decline due to an irreversible or terminal process or one that is potentially reversible?" If it is likely to be irreversible, we offer comfort care options to the person in transition. If the decline is due to a process that is potentially reversible, we offer explicit diagnostic and therapeutic options and the most likely outcome for each option. We honor our older patients by giving them and their families the opportunity to choose among these options. By taking this approach, many of the older adults we attend and the family members who love them can find peace by making life-enriching rather than life-extending choices.

MEDICAL HUMANITIES REPORT

The Center Welcomes

The *Medical Humanities Repor*t would like to welcome Gerald S. Schatz, JD, and Dr. Margaret Holmes-Rovner, two new faculty who have joined the Center for Ethics and Humanities in the Life Sciences this spring. We look forward to the energy they will contribute to CEHLS through their research, teaching, and community outreach.

Gerald S. Schatz, JD has been appointed Assistant Professor in the College of Human Medicine and Center for Ethics and Humanities in the Life Sciences. He is a lawyer, ethicist, and policy analyst, with a background in biomedical ethics, science policy, and domestic and international public law and includes experience at the U.S. House of Representatives, the National Academy of Sciences, the National Science Foundation, and the Georgetown Center for Clinical Bioethics, where he has been a Visiting Scholar.

Jerry has served on ethics review committees of the National Institutes of Health, and he developed and taught the Biomedical Ethics Law course at the Graduate School of the Foundation for Advanced Education in the Sciences, at the National Institutes of Health. His teaching and research interests are in the interrelationships of law and biomedical ethics and in protection of human subjects of biomedical and behavioral research. His recent work includes "International Law and Biomedical Ethics" in Giovanni Russo's new *Encyclopedia of Bioethics*, and "Are the Rationale and Regulatory System for Protecting Human Subjects of Biomedical and Behavioral Research Obsolete and Unworkable, or Ethically Important but Inconvenient and Inadequately Enforced?" in the *Journal of Contemporary Health Law and Policy*.

Margaret Holmes-Rovner is Professor of Health Services Research. Her research focuses on improving the quality of health care in the US, and patient-provider communication and shared decision-making. She teaches health policy, and ethics in the pre-clinical and post-graduate programs of the College of Human Medicine. Margaret received her PhD in curriculum and sociology at the University of Wisconsin in 1980, and joined the faculty of Michigan State University in the Office of Medical Education Research and Development in medical decision making the same year. She joined the Department of Medicine in 1986, and was Chief of the Division of Health Services Research from 1995-2005. She joined the Center for Ethics and Humanities in the Life Sciences in February, 2005, and is finalizing a joint appointment in the College of Nursing. She has served in leadership positions in academic governance, including Chairing the University Committee on Faculty Tenure, and the Women's Advisory Committee to the Provost. She received the College of Human Medicine Outstanding Faculty Award in 2002 and the Department of Medicine, Outstanding Researcher in 2003.

Margaret has served in a national leadership capacity in the field of medical decision-making and technology assessment. She was the first woman elected to be President of the Society for Medical Decision Making, and served in many other roles in the Society, receiving the Eugene Saenger Award for Distinguished Service in 1999. She has served on many journal editorial boards, policy commissions and grant review panels for the CDC, NIH and Agency for Healthcare Research and Quality, serving as Chair of the Health Care Technology and Decision Sciences Study Section of the Agency for Healthcare Research and Quality from 1999-2003.

At an international level, Margaret is a founding member of the Shared Decision Making Forum-2000, funded by the Nuffield Trust to increase collaboration between North America and the United Kingdom (UK) in development, evaluation and implementation of shared decision-making. Her research focuses on descriptive and prescriptive studies of patient and physician decision-making. She has developed decision support tools, and decision aid evaluation measures, and presently serves as chair of the Health Literacy Expert Panel of the International Consensus on Standards for Developing and Evaluating Patient Decision Aids. Her other on-going scholarship is in the areas of health literacy, chronic disease management, and use of the electronic medical record (EMR) to facilitate patient participation in decision-making.