

University of Miami Law Review

Volume 61
Number 3 *Volume 61 Number 3 (April 2007)*
SYMPOSIUM The Schiavo Case:
Interdisciplinary Perspectives

Article 10

4-1-2007

Ethics Schmethics: The *Schiavo* Case and the Culture Wars

Kenneth Goodman

Follow this and additional works at: <https://repository.law.miami.edu/umlr>



Part of the [Family Law Commons](#), [Health Law and Policy Commons](#), and the [Medical Jurisprudence Commons](#)

Recommended Citation

Kenneth Goodman, *Ethics Schmethics: The Schiavo Case and the Culture Wars*, 61 U. Miami L. Rev. 863 (2007)

Available at: <https://repository.law.miami.edu/umlr/vol61/iss3/10>

This Transcript is brought to you for free and open access by the Journals at University of Miami School of Law Institutional Repository. It has been accepted for inclusion in University of Miami Law Review by an authorized editor of University of Miami School of Law Institutional Repository. For more information, please contact library@law.miami.edu.

SPEECH

Ethics Schmethics: The *Schiavo* Case and the Culture Wars

KENNETH GOODMAN¹

One of the things that's nice about living in Florida – in fact those of us who are natives really do love it and even get defensive of it – is the frequency with which things that are kooky happen. “Kooky” is a technical term in ethics; we use it to describe circumstances that tend to resist rational analysis. The *Schiavo* case is, of course, quite serious, and so to say “serious” and “kooky” in the same breath is oxymoronic. It is, however, what we are stuck with. If one wanted to redesign the state flag of Florida, the result would resemble a hanging chad – on one side would be an image of Elian Gonzalez, and on the other side would be Terri Schiavo – with the whole thing flapping in a hurricane's gales. What I want to do here is to defend our beautiful state against some of the calumnies that have been hurled against it, and make a couple of points about the importance of this case in law, in ethics, and in the daily practice of people in medicine, nursing, and health law. There are three main points I want to make. One of them addresses the history of end-of-life practice in ethics and law in Florida until the *Schiavo* case. The second will be the effects of politics on that process. And the third part will look a little bit at what the case will mean in the future.

Let me begin therefore with the history. It is worth mentioning that in terms of foundational issues having to do with end-of-life care and the right to say “no” to burdensome treatment, these issues had, I believe, been largely settled – not just in Florida, but elsewhere, too. There was broad agreement in the medical community, broad agreement in the legal community, and broad agreement in the ethics community that would suggest that the *Schiavo* case should have been uncontroversial. The clearest cases are those in which there is a patient who is adequately informed, making a voluntary decision, and capacitated enough to understand and appreciate that decision. If that patient says he or she doesn't want a particular intervention – including a lifesaving intervention – then the right and legal thing to do is withdraw or withhold the

1. Associate Professor of Medicine and Philosophy, University of Miami; Co-director, University of Miami Ethics Programs; Director, University of Miami Bioethics Program.

treatment; in other words, the patient has the right to refuse treatment. If you're a physician, you might say, "work with me, Ken. We can get you over this little hump." But at the end of the day, "no" means "no." Informed consent is a hollow and fatuous entitlement if one doesn't get to say "no" to unwanted treatments. It is also widely and uncontroversially agreed that if for some reason I'm not able to consent to or refuse treatment myself, then someone needs to do it for me. People in those positions are ideally people I appoint – my brother, my sister, whomever. In the best possible world, I will first communicate with that surrogate regarding my end-of-life values, my tolerance for a life of complete mental incapacity, and so forth. My surrogate can then make judgments for me given my incapacity. That is the gold standard for surrogate decisionmaking – substituted judgment. Surrogates must decide and act based on the patient's values, not their own. It's not about them; it's about me. My surrogate must channel me, as it were, given my inability to communicate my wishes, requests, or refusals.

Having failed to appoint someone to make judgments for me, Florida statutes, as do those of forty-nine other states, lay out an order of proxies. (Florida apparently uses the terms backwards: in several other states, "proxies" are appointed and "surrogates" are enumerated by statute.) In any case, chapter 765, Florida Statutes, lays out that proxy order. After a court-appointed guardian, of course, the first person in Florida, as everywhere else, is the spouse, if there is one. Why? Especially in the case of adults, there is ample evidence that the parents of adults are notoriously poor decisionmakers for their children. It is very, very difficult to be involved with a life-or-death decision involving your own child. And so it made perfect sense in the *Schiavo* case that Michael Schiavo, her spouse, would be that person.

The history in Florida shows the evolution of a law that was bipartisan and nonsectarian; hands reached across the water and across the aisle. Several years ago Florida established a Panel for the Study of End-of-Life Care. A former secretary of health led it; he was a legislator and physician, as well. Statewide organizations collaborated on the panel and made a number of important changes to chapter 765. Unanimously agreed upon by bipartisan House and Senate committees, the legislature affirmed the right to refuse treatment (and, moreover, urged that worry about the side effects of aggressive pain management not impede patient care).

It's important that people understand that aggressive pain management is good and appropriate for patients who are in pain. And it is important that the physicians who are concerned that they might be overprescribing certain drugs – witness the U.S. Supreme Court's ruling

in *Gonzales v. Oregon* – understand that it is not a problem to prescribe aggressive doses of pain drugs, even if there is some chance that the drug might cause an unintended side effect, including death of a patient. That is not euthanasia, that is not assisted suicide, that is not any such thing – no more than it would be if a cancer drug, say, had adverse effects, no more than if a patient had an allergic reaction to the dye they inject in veins for imaging studies. Patients die of unintended side effects all the time, and if every time they died when it was no one's fault and that constituted euthanasia, we'd have to shut down our hospitals. So we had hands across the water, bipartisan agreement, and enjoyed the revision of a law – chapter 765, Florida Statutes – that is regarded by some around the country as quite a good model.

It's against that background that end-of-life decisionmaking in Florida is evolving. In fact, it was during the middle stages of the *Schiavo* case when that statewide panel did its work. As the lawsuits began to be filed in earnest, we were watching and thinking, "that's interesting . . . not sure what's to be done about this." It became extraordinary, we now know, not because of anyone's moral commitment, but rather because partisans found they had the resources to make this a *cause célèbre* for reasons independent of the rights of Terri Schiavo. In other words, it became clear to a number of people in the political community that Florida's gentle and delicate balance was something they were prepared to upset to make political hay. Of all the lawsuits that were filed, most of them were financed by partisans with an ax to grind. That is to say, nationwide organizations affiliated with political, pro-life, and other organizations, including eventually disability organizations, were in fact sponsoring much of the furor. The filing of lawsuits did a number of things: first, it prevented Michael Schiavo from doing what he thought would represent his wife's wishes and so prevented him from doing what he needed to do in following the standard of substituted judgment, that is, withdraw artificial nutrition and hydration; second, it gummed up the works.

It is worth making an observation similar to an interesting point Professor Levi made about the news media; I find that the ability to manipulate images may be among the most important lasting lessons here. What you learned from Dr. Cranford, and especially from the slide he showed us, was that Terri Schiavo's cerebral cortex was full of spinal fluid. Moreover, a flat EEG means that the part of your brain that's supposed to do the thinking is not working. It means, as the autopsy showed afterward, that this woman for fifteen years could not see, feel, hear, or experience anything. (This is not to insult her, and it is not to say a bad thing about her; it is only to point out the brute facts of the

matter.) The upshot is that she couldn't see, and if she couldn't see, she couldn't follow a balloon. The videos used to shape, to *beguile*, public opinion were bogus. It is a very important message.

The video clips we all repeatedly saw made (some) reasonable people think, "yes, I really believed I understood this case, but since I saw that video, it's really been bothering me. I now understand why the Florida legislature started engaging in civil disobedience – because legislators thought they were doing the right thing. *Just look at the videos.*" And every time CNN, and every time Miami-based Channel 4, and every time everyone else showed the video, they were lying. Well, they might not have been lying, because they didn't know what the truth was – you have to know that something is false in order for it to be a lie – but they were contributing to a deception that was in fact intentional at one point or another, namely, "how can we best confuse people with this image?"

How many of you remember when the first space shuttle blew up almost exactly twenty-five years ago? There was a very powerful image of Christa McAuliffe's father looking up into the sky as her spacecraft was exploding. As he's looking up into the sun, he's grimacing. But the grimace – and Dr. Cranford can explain how this works – has the corners of his mouth turned up because he's squinting into the sun. This picture was on all the wire services and transmitted broadly. The problem is that it made it look like he was grinning. He wasn't grinning. He was watching his daughter being blown up in a spaceship. That kind of lower-brain activity made it look like Terri Schiavo could actually be smiling and interacting when in fact no such thing was happening. The fact that the news media missed this is among the greatest tragedies in this case.

I believe that a lot of people in the Florida legislature at the time actually believed they were voting their conscience in passing, for example, Terri's Law – an extraordinary bit of legislation applied to one person in a particular case, and of course later found to be unconstitutional. The measure at one point led to the reinsertion of her percutaneous endoscopic gastrostomy tube. Make no mistake, by the way, that this is not a cup of water. It is a surgical procedure which has become quite common. Dr. Cranford was right: twenty-five years ago, we didn't even do them. The first one in Florida was performed twenty-two years ago by a physician at the University of Miami, and it was recognized in all cases to be a bridge to recovery for people with swallowing disorders. It is interesting how science progresses, and now these artificial hydration and nutrition tubes have become the sort of thing you need to go out of your way to refuse. So that's the history, with a little bit of annotation,

if you will. Hands across the water, most everybody is collaborating, and then along comes this awful case.

Now, the case has morphed in ways I've tried to describe and I think others have, too. The physicians who wrote the autopsy report were not anarchists; they were doctors practicing in Florida. They said she had no cerebral cortex and therefore couldn't see because the part of the cortex controlling vision was missing. Therefore, she couldn't have been watching the balloon, and the people at the time who made the video and released it knew that.

The ethical issues raised by the case were standard sorts of ethical issues, at least early on. They had to do with capacity, they had to do with decisionmaking under incapacity, and they had to do with the right to refuse treatment, as well as questions about surrogates doing so. In Florida and elsewhere, these were often settled issues. Extraordinary things had to happen to move this case and make it the extraordinary case that it was – the case that went to Congress and saw the president flying to the capital in the middle of the night to sign legislation. By the way, Ms. Schiavo was at one point subpoenaed by Congress. That is, a person in a persistent vegetative state was ordered to testify before the Congress of the United States of America. I can say with some authority that she completely ignored that subpoena, and what's to be done about that, I don't know. Perhaps she could have been found in contempt.

In any event, what became extraordinary were the opportunities and the resources devoted at every point along the way to try to find a chink in the armor: the neurologists said that she was in a persistent vegetative state, which was medically uncontroversial – so political partisans and religious extremists claimed the neurologists were wrong; the husband said what he believed his wife wanted and a series of judges said that's the right thing – and the extremists then labeled the husband a jerk; the courts themselves, up to the Supreme Court of the United States, said it seems like there was no traction here, they had nowhere to go legally – so the partisans claimed the courts had become agents in the murder of an innocent woman and were practicing "judicial activism." At every point along the way, whenever one path was exhausted, there was a creative opportunity to file a lawsuit to try to explore another one. I think the ethical, the healthcare, the medical, and the bioethical issues were straightforward and easily resolved. I think Professor Winick will talk a little bit later about some of the legal issues, namely, how the extremists managed to find or invent fodder for as many lawsuits as they did in a comparatively short time. The idea that you could file that many lawsuits given this environment, I think, is a wonderful opportu-

nity for students here to discuss the lengths one should go for a client when one's client is willing to pay for you to do that sort of thing.

The *Schiavo* case became political also because of the language that was used. You heard earlier that people talked about "murder" and "starvation." Ms. Schiavo's death was, of course, no such thing. People die all the time as a result of having artificial nutrition and hydration removed. It is not painful; it is not distressing, unless you're a family member watching it. The patient him or herself can do this with dignity; *it happens all the time*. We are actually still allowed to die in Florida, and sometimes there's just nothing to be done about it.

But, the language of starvation and of murder and killing was the language the news media decided had to constitute "the other side of the story." The greatest criticism that I would like to offer – which actually follows on Professor Levi's points – is that the news media weren't biased – they were fatuous. They teach you in journalism school and in newsrooms, where I will confess to having spent a decade, that you've got to make sure you multi-source your reports and show balance. And, in this case, the only sources of "balance" were political outliers. They were, as you saw in Dr. Cranford's slide, vitalists, people who hold the belief that despite the absence of cognition of any sort, a beating heart in a permanently unconscious human needs to be protected the same way as a beating heart in a human who has cognition and sentience. It is actually a fundamentally primitive belief, and no one really held it, we didn't think, until the *Schiavo* case.

Extremists of political and other sorts sought the limelight, but when Jesse Jackson showed up at Terri Schiavo's bedside in a sign of solidarity, you could have heard the jaws drop all around Florida. The point is that balance doesn't mean there are always two sides to the story. What if I came to you as editor and asked you to do a balanced, pro/con piece on drunken driving? Or what if I asked for a piece on sex with children? There's actually an organization that advocates sex with children. As a journalist, would you use that as a source to provide balance on a story about pedophilia? No, you wouldn't – because sex with children is wrong. Because someone is out there to advocate for something doesn't mean that you thereby obtain credible balance.

The disability community, I believe, was completely hoodwinked and boondoggled. Duty-bound to protect the interests of the differentially abled, the disability community was by and large convinced that Ms. Schiavo was one of them and hence deserving of protection. But Ms. Schiavo was not disabled on any technical or ordinary reading of the term. To be permanently and utterly unconscious is perhaps to be many things, but it is not to be differentially abled. Worse, once

appointed part of the “save Terri” team, the disability community found itself in alliance with forces which had shown no previous interest in the needs of the disabled – forces which could blithely cut taxes for programs needed by this very community. Make no mistake, the *Schiavo* case became a “moral resort area” (in Saul Bellow’s famous words) for people who want simultaneously to talk about commitment to vulnerability but for some reason are completely unwilling to write the check.

I see in a newspaper from last week that “nearly a year after calling for federal involvement to keep a brain-damaged woman alive against her husband’s wishes, Republican Senator Mel Martinez said it was a mistake to become involved,” according to the Associated Press. Senator Martinez, who just completed his first year in office, led the Senate charge, pushing a bill that would’ve given federal courts jurisdiction to reinsert Ms. Schiavo’s feeding tube. Martinez said, “if I had to take one lesson away, it’s perhaps that decisions of this nature really belong in state courts, not federal courts, and that ultimately this was not a federal case and shouldn’t have been.” He could’ve gone further and said that this is actually something family members have customarily decided on their own, thank you very much.

Nevertheless, legislation (since defeated) had been introduced to try to change chapter 765 by requiring that advance directives need to specify precisely which medical interventions one intends to refuse, namely, a PEG tube, a ventilator, or any other thing. This would need, of course, to be specified in advance, along with a statement of the precise circumstances under which one intended them to be refused. Such a measure would completely undermine everything we think we know about advanced care, everything we think we know about advanced directives, and everything we know about the right of free people to say “no” to burdensome interventions. It is worth mentioning that across the spectrum, not just politically, but according also to mainstream branches of major faith traditions – in Christianity, in Islam, in Judaism – there was broad agreement that morality permitted the removal of Ms. Schiavo’s artificial sustenance. In Catholic hospices around the country, for instance, staffers were concerned that such legislation would require them to force treatment on patients who did not want it, when in fact there’s neither scriptural nor any other requirement that one must use a machine against someone else’s wishes.

Ultimately, the culture wars have leaked a little too far into our daily lives, particularly with respect to the vehemence with which this debate was conducted and the way it was moved forward based on ultimate medical falsehoods and views and values that are really quite peculiar – outliers to our own communities. One state senator, a Florida

Republican who had been active and very interested in these issues, was made to weep on the floor of the Florida Capitol, having been accused by people of contributing to the murder of Terri Schiavo. That was *pre-posterous*, and anyone who tries to suggest otherwise is trying to bamboozle you for craven and occult political purposes.

What we value about life is cognition, communication, interaction; we enjoy this, and it is what makes life precious. And make no mistake, it is precious, which is why we need to find better resources to take care of people who are in fact vulnerable and need our help. What we value about life, though, is cognition, communication, and interaction. What do not value is simply that we are not dead. That point was clear to many who felt slimed by the entire process – and it provides a tool, a fulcrum, for those of you who will be practicing law in the future. Sometimes there are opportunities for the skills of critical thinking and ethics not only to accommodate reasonable disagreement, but also to prevent the corruption of debate by extremists who use the language of ethics and justice, but who actually have other axes to grind.

Thank you.