

Comment

A matter of life and death

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Published: 28 April 2005

Genome Biology 2005, **6**:109 (doi:10.1186/gb-2005-6-5-109)

The electronic version of this article is the complete one and can be found online at <http://genomebiology.com/2005/6/5/109>

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Terri Schiavo died at 9:05 on the morning of March 31, 2005. That's what her death certificate says. Thirteen days previously, at the request of her husband, Michael Schiavo, who said he was carrying out her wishes, her doctors removed the feeding tube that was keeping her alive. Without food or water, she eventually succumbed to heart failure at age 41. The death certificate doesn't come close to telling the real story of her death, however. Some people, including her parents, siblings, and a number of religious and political figures, would probably claim that, on that morning, Terri Schiavo was murdered, either by her husband or her doctors or both. Others think she should have been allowed to die at least seven years earlier, when her husband first requested it. And then there are those like me, who believe that on the morning of March 31, 2005, Terri Schiavo had already been dead for fifteen years.

Terri Schiavo (born Theresa Marie Schindler) was a young married woman of 26 when she went into cardiac arrest, possibly as a result of potassium imbalance brought on by an eating disorder. When her heart stopped, she lost oxygen to her brain for a considerable period of time before emergency medical personnel were able to restart it. From that moment on, Terri Schiavo never uttered a word, made a voluntary conscious movement (she exhibited involuntary reflex actions only), or responded to any external stimuli. Neurologists who examined her said she was in what they term a "persistent vegetative state", a condition that sounds as bad as it is. Her electroencephalogram (EEG) was flat, indicative of no higher cortical functions. A brain scan indicated that essentially all of her neurons were dead - presumably from apoptosis due to ischemia. Her brain stem still functioned, though, and such is the persistence of the autonomic nervous system that her lungs continued to work and her heart continued to beat for fifteen years. But there was no mind. Some years after she went into this condition her husband lost hope and petitioned the Florida courts to allow her feeding tube to be removed. The courts agreed, but her parents, the Schindlers, who never lost hope that a miracle

could still happen, obtained an injunction preventing the tube's removal. The husband appealed. The appellate court sided with him; the Schindlers sought another injunction, and so on, back and forth year after year: a legal tug-of-war with a brain-dead woman as the rope.

Something like this can bring out both the best and the worst in human nature. The Schiavo case certainly did. For the best one only has to look to the health-care workers at the hospice who nursed the body of Terri Schiavo, gratis, for over a decade. Or perhaps to Michael Schiavo - if, as he said, his motivation was to carry out Terri Schiavo's wishes that her life not be prolonged artificially if something like this ever happened to her. Some would also look to the Schindlers, who, having convinced themselves that their daughter's condition might someday improve, did everything they could to keep her alive. (In any case, I certainly think one has to feel enormous pity for them. No parent should ever have to bury a child. To lose one's parents is the way of the world, but to lose someone young like that is like being cheated.)

As for the worst, sadly there are a number of contenders. The radical right-to-lifers and religious fundamentalists who intruded on what should have been a private family matter would surely garner plenty of votes. They seem to crawl out of the woodwork whenever a case like this can guarantee them publicity. Shamelessly preying on the Schindlers' grief and hope, they turned the whole affair into a media circus, with themselves as ringmasters.

But my vote for the conscienceless opportunism prize goes to those Congressional politicians who, seeing a chance to cater to their social conservative constituents, passed an *ad hoc* law referring the Schindlers' case to the Federal courts (which normally have no jurisdiction in such matters) in a display of pandering that hasn't been seen since Pandarus gave the activity a bad name. President Bush was also quick to use the sorry situation for his own political display: he

could have signed the law at his Texas ranch, where he was vacationing at the time, but instead flew back to Washington so he could affix his signature in front of the maximum number of television cameras. Worst of all were the Republican leaders of the Senate and House of Representatives, respectively Bill Frist and Tom DeLay. DeLay, currently under investigation for several breaches of ethics (perhaps that makes him an expert on the subject), led the fight in Congress to take the Schiavo case to the Federal courts (which, in the end, upheld the state court rulings in favor of her husband) despite decades of legal precedents establishing such cases as state matters. "The time will come," he said, "for the men responsible for this to answer for their behavior. We will look at an arrogant, out-of-control, unaccountable judiciary that have thumbed their nose at Congress and the president." (Congressman DeLay seems to have overlooked the fact that thumbing their nose at Congress and the president is exactly what the judiciary is supposed to do - the US Founding Fathers called this the separation of powers in the Constitution. Perhaps he ought to try reading that document sometime.) And Bill Frist, an MD who was a transplant surgeon before entering the Senate, actually performed his own neurological examination by viewing a videotape of Terri Schiavo and then pronouncing her condition not as bad as the experts had stated. No neurologist would ever make a diagnosis without actually examining the patient in person.

Many commentators expressed amazement that Congress should have chosen to intervene in such a deeply personal dispute, but that didn't surprise me at all. Since many politicians have been in a persistent vegetative state for decades it seems only natural that they would identify with someone in that condition. If so, they had company: one vocal group of supporters for keeping Terri Schiavo alive were activists for disabled persons. Some of them apparently feared that the decision to let her die might be the first step down a slippery slope, leading eventually to the 'right to die' becoming an 'obligation to die' for the severely disabled. But Terri Schiavo wasn't in a wheelchair, or blind. By any reasonable definition, her condition was not a disability. To argue that this case had anything to do with the rights of the disabled is to force it into a mold it doesn't fit. For me this illustrates one of the main problems I have with activists in general: their frequent tendency to distort reality, probably because they see everything through the lens of their particular single issue.

You might wonder why I appear to dismiss the possibility that the politicians were motivated by a sincere moral principle, namely a belief in the sanctity of human life. I do think some of them, and many of their supporters, were - but the evidence points against it in the case of many of them. For me, the acid test for the presence of principles is a certain moral consistency, because that indicates there is something underpinning the decisions one makes. Moral cognitive dissonance - the holding of two opposing positions at the same

time - strikes me as a pretty good basis for concluding that opportunism is at work. Most Congressmen who voted for Federal intervention in the Schiavo case were also staunch supporters of the war in Iraq. Perhaps their respect for life only includes Judao-Christian life. Yes, I do understand one might argue that it is sometimes necessary to sacrifice some lives to preserve many more. But most of these same politicians are also strong supporters of capital punishment (the death penalty), which has never been proven to save lives and, in the US, disproportionately falls on the poor and the black. Do we then conclude their respect for life is restricted to white, Judao-Christian life from the middle class on up?

It has been suggested that the Schiavo case is one more piece of evidence of the hijacking of the Republican Party by the religious right. John Danforth, a former Senator and a moderate Republican - now there's a phrase that may be rapidly becoming an oxymoron - argued just that in an opinion piece in *The New York Times*. If so (and I have my doubts that this really does constitute such evidence - not least because some 50 Democrats voted in favor of the DeLay-sponsored bill, and many Roman Catholics, who are not knee-jerk social conservatives, also supported Terri Schiavo's parents), the religious right may have overreached this time: opinion polls indicate that almost 80% of Americans opposed Congress getting involved in this case. Still, there's little doubt that social conservatism is on the rise in the US. Fueled in part by a deep suspicion of scientific advances, especially in biology, a significant number of Americans are expressing doubts about the morality of abortion, stem-cell research, the creation of chimeric animals, and many of the anticipated fruits of the genomics revolution. Evangelical Christians accounted for over a quarter of George Bush's vote in 2004, according to John Green of the University of Akron, and if you include doctrinaire Catholics, then religious conservatives made up over 40% of his total. No administration can ignore such supporters.

But for me, what is most striking about the Schiavo case is that it once again shows the importance of framing the issues properly. An enormous amount of energy, angst and verbiage has gone into a debate about whether or not it is 'right' to end the life of a patient who will never recover cognitive functions. That shouldn't be the issue here at all. Whether or not Terri Schiavo (or any other persistently vegetative patient) ought to have been allowed to die is completely beside the point. The point is, she was dead to begin with.

Someone who will never be able to form a thought, respond to the outside world, and initiate a voluntary movement should never be considered alive by any reasonable definition of the word. But advances in medical technology have allowed us to keep such a person's heart beating for essentially a normal life span. Our ability to sustain some of the outward signs of life has rendered obsolete the legal system's definition of what it means to be alive. Since it is unlikely

that this definition will change any time soon, it is incumbent on every individual to make clear exactly what he or she considers being alive to mean.

Many have tried to do so, through the use of 'living wills' - documents that set forth their wishes regarding the use of extraordinary measures to sustain life should something dreadful happen to them. Though such wills have no force in statute, courts and hospitals often take them into account in making judgments about treatment. But one lesson of the Schiavo case is that such language may not be enough, especially in cases where family members, often motivated by sincere efforts to do the best thing for their loved one, fail to agree on what is that best thing. To increase the likelihood of avoiding such conflicts, living wills need to designate a healthcare proxy: someone who is empowered to speak on behalf of the patient when he or she can no longer speak for themselves. It's a good idea for such a person to be as objective as possible, so a close relative might not always be the best choice. Living wills should also spell out, in no uncertain terms, under what conditions a person considers their life to have ended.

Social conservatives have been energized by the Schiavo case, and now seem poised to try to impose their moral values on society through legislation. Our old friends Tom DeLay and Bill Frist are in the vanguard of this movement. "It is not a day we will forget," said DeLay. "We will work as hard as we can to stop this from happening [again]." Right-wing religious groups have vowed to push for new laws restricting when spouses or relatives can end life-sustaining care for an incapacitated person, and for changes in the rules of the Senate that will more easily allow the ruling Republican Party to confirm conservative judicial appointments by the president. Ten US states are also considering legislation that would block termination of life-support measures, unless all legal appeals are exhausted and there is written consent from the patient (a living will).

Just because something is done in the name of God doesn't automatically free it from the possibility of being tyrannous. The dictatorship of the self-anointed morally righteous is still a dictatorship. On one point, however, social conservatives and I agree: life is a thing of great value. In fact, it's far too valuable to allow it to be controlled by a bunch of sanctimonious hypocrites. No one has the right to say what's to be done at the end of my life unless I give them that right. So as soon as I finish this column I'll be updating my living will to name a healthcare proxy. I'm also going to specify under what conditions I believe my life to be over - and that then I wish to be treated accordingly: namely, make me as comfortable as possible and let me go. I will certainly stipulate that I should be considered dead if I am diagnosed by reputable neurologists to be in a persistent vegetative state. And I think I'll add that I should also be considered to be brain dead if I ever start acting like the leadership of the US House and Senate.