

Could Alternative Medicine Have Saved Terri Schiavo?

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When Terri Schiavo finally died on March 31, 2005, it was amid an avalanche of controversy set off by several differing points of view that had dominated the airwaves for weeks. The religious right spoke about Terri Schiavo's "right to life." The American Civil Liberties Union defended her husband's right to carry out her wishes as he saw them.

Bioethicists, without using the term, introduced the public to the theory of "Futile Care," which states that if a patient is deemed by treating physicians to be in a hopeless condition, medical care may be denied—over the objections of the patient's family.* And doctors and lawyers used this sad affair as an opportunity to educate people about living wills and powers of attorney for health care.

But there is one message that should have been brought out front and center—a message that might have saved Ms. Schiavo's life, as well as the lives of other patients who are routinely allowed to die in institutions in this country. The message is: There are cutting-edge treatments (and one in particular) that many proponents of alternative and complementary medicine (ACM) strongly believe might have improved Ms. Schiavo's condition and perhaps offered her an excellent chance for a more aware quality of life.

Alternative and complementary practitioners should be concerned about this case on many levels. Another lesson to be learned from this case is that if a patient of yours becomes hospitalized as the result of a stroke or other kind of brain injury, and is "not responsive," the doctors and nurses at that institution will define, with their own tests and without your input, whether or not "brain death" has occurred.

And if they do diagnose "brain death" or "persistent vegetative state," it is likely that, as with Ms. Schiavo, alternative treatments (even those that are cutting-edge) will be denied—even if

you want your patient to get them. In fact, there is a good chance that the Futile Care option will be exercised by the doctors in the hospital—over your objections.

Partly because of her husband, Michael Schiavo, and partly because of the so-called "standard of care" in hospitals and other medical facilities in this country, Ms. Schiavo was never given the single-photon emission computerized tomography (SPECT) scan that could have possibly predicted whether or not she could have "recovered" as a result of any alternative treatments.

Standard of Care for Brain Injury

The term standard of care in no way connotes excellence, as many people seem to think it does. Rather, it refers to a consensus among conventional doctors as to which treatments are, or are not, appropriate for a particular condition. And that standard includes not being allowed alternative treatments in hospitals and other conventional medical facilities.

Even if the physicians and judges involved in this case had known that a SPECT scan can accurately measure relative brain blood flow and strongly indicate a person's likely recoverability from neurologic damage or dysfunction, it is likely that this scan would have been denied. Nor would the physicians and judges have permitted Ms. Schiavo to receive any of the treatments that might have improved her functions. These treatments and tests, of course, are not considered standard of care in the United States for patients with severe brain injury.

Several prominent physicians, conventional and alternative, submitted affidavits to the court, expressing their beliefs that Ms. Schiavo's neurologic function could have been recovered significantly (these affidavits are prominently displayed at <http://www.terrisfight.org/>). Why were they summarily dismissed?

Hyperbaric Oxygen Therapy

Brain injury, a condition for which conventional medicine has very little to offer, is one of the conditions for which alternative medicine can offer some particularly effective treatments. The most notable of these treatments is hyperbaric oxygen therapy

*For a more complete discussion on the concept of Futile Care, see *Culture of Death: The Assault on Medical Ethics in America*, by Wesley L. Smith (San Francisco: Encounter Books, 2000).

(HBOT), which has been used by alternative practitioners to treat such neurologic conditions as stroke, brain injury, cerebral palsy, and coma, since 1972. HBOT is currently being used to treat brain

injury in other countries, including Russia, China, Japan, Italy, England, and Scotland.

Richard Neubauer, M.D., the medical director of Ocean Hyperbaric, Lauderdale-by-the-Sea, Florida, is considered by many people in this country and worldwide to be the "Father of Hyperbaric Oxygen for Treating Neurologic Conditions." Dr. Neubauer recently stated: "It is my belief that Terri Schiavo could probably have been recovered. At least she should have been given that opportunity."

In 2001, Dr. Neubauer submitted an affidavit to the court, in which he said he felt it was tantamount to murder not to give Ms. Schiavo this chance. He submitted another affidavit to the court in 2005 and offered to treat her without any fees. "Quite frankly," Dr. Neubauer says, "in Europe, such options would have been given greater consideration."

Many of the people Dr. Neubauer has trained now run successful HBOT clinics throughout the United States and the world, and he gets calls from doctors all over the world, asking him specific questions about how to treat specific patients. Dr. Neubauer wishes that conventional U.S. physicians would be more open-minded. "Unfortunately," he says, "in America, it's all about money, and there is no real money in HBOT. We live in a pharmaceutical society," in which, he notes, pharmaceutical therapies are the norm.

However, Dr. Neubauer feels that HBOT's cost effectiveness for people with brain injury is compelling.

According to Dr. Neubauer, and many other doctors, the following should have been done for Ms. Schiavo: She should have had a SPECT scan; followed by a trial of hyperbaric oxygen; followed by a repeat SPECT scan. If the repeat SPECT scan showed recoverability (defined by idling, rather than dead, neurons), she should have been given a series of hyperbaric oxygen treatments. Had she been given HBOT years ago, when she first became brain-injured, there is a possibility that the subsequent damage could have been averted. According to several doctors I spoke with, many patients in comas have been "brought out" this way, but it is not covered by insurance in the United States.

This method (SPECT, trial HBOT, repeat SPECT) was developed in 1990 by Dr. Neubauer and is now becoming the accepted method of measurement of brain activity and recoverability by many conventional practitioners in other parts of the world and by some alternative practitioners in the United States. This method demonstrates blood flow and metabolism clearly, and many practitioners feel that it is the most accurate determinant of brain death available to date.

Why HBOT Was Denied

Why was Ms. Schiavo not evaluated and treated in this way? Strict legalists say that it was because her husband did not want her to be treated at all, and that, as her legal guardian, this was "his right." But, in 2002, her parents called on William Maxfield, M.D., (at the time affiliated with the Manatee Diagnostic Center, Bradenton, Florida), one of the early pioneers (with Dr. Neubauer) in using HBOT for neurologic conditions, to testify at an evidentiary hearing. This hearing was, according to the court, "only for

Resources for You and Your Patients

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the purpose of assessing her current medical condition, the nature of the new medical treatment[s] and their acceptance in the relevant scientific community, the probable efficacy of these new treatments and any other factors the trial court deems relevant."

After hearing Dr. Maxfield, the judge ruled against trying HBOT, calling it "experimental insofar as the medical community is concerned with regard to patients like Terri Schiavo, which is borne out by the total absence of supporting case studies or medical literature." He went on to rule that there was "no such testimony" that would lead him to think that HBOT "offers such sufficient promise of increased cognitive function in Mrs. Schiavo's cerebral cortex so as to significantly improve her quality of life."

It is not the case, however, that there is "no evidence" of the efficacy of HBOT for treating neurologic conditions. Dr. Neubauer has conducted numerous scientific studies, and has published his results in respected mainstream medical journals, including: *The Journal of the American Medical Association*; *American Family Physician*; *Stroke*; *The Lancet*; *The Journal of Clinical Medicine*; *The Journal of Hyperbaric Medicine*; *The Journal of Neurosurgery*; *Physician*; and *Sports Medicine*. In addition, he is a sought-after international lecturer, who has taught at educational seminars in the United States, France, Italy, Austria, Cuba, and China.

Why did the judge rule this way—despite existing evidence to the contrary? According to Dr. Maxfield, the court did not seem to be interested in learning about hyperbaric oxygen at that hearing.

But there are possible reasons: In the United States, HBOT for neurologic conditions has more detractors than many other holistic treatments. Also, many conventional doctors in this country are not learning more about HBOT—even though their conventional treatments have very limited success. More significantly, a powerful group of M.D.s, the Undersea and Hyperbaric Medical Society, is committed to making sure that insurance only covers hyperbaric oxygen when it is used for 13 specific conditions. Brain injury is not one of them.

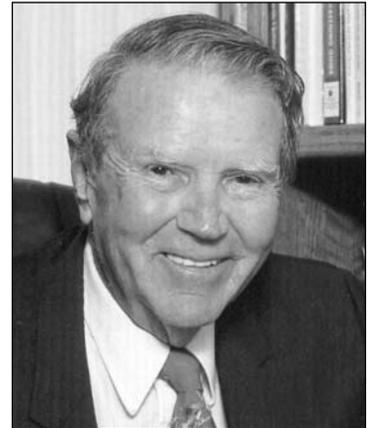
These conventional doctors are the ones most often quoted in the press, since they provide the standard of care as practiced in this country. And whenever an article appears in the press, describing a person who has been successfully treated with hyperbaric oxygen for brain injury or stroke, these doctors are usually quoted, often at the end of the article—almost as an obligatory add-on. And, of course, they say there is "not enough evidence. We need more studies." These doctors' opinions on this topic have great influence in the courts.

What Hospitals Do

The Schiavo case is an extreme example. Most patients, it is hoped, will not be hospitalized with strokes or severe accidents that cause brain injury. But many of your patients will be hospitalized, and it is likely that they, too, will be subjected to the conventional standard of care. For example, patients today are

routinely not "allowed" to take their vitamins in the hospital.

What is even more troubling, says Richard Jaffe, J.D., a Houston, Texas based—health care litigator whose primary focus is on cutting-edge medical/legal cases, is that patients with cancer, undergoing unconventional treatments for their cancers, are not allowed to take their cancer-fighting drugs while in the hospital. Why? Because those drugs, which are most often far less toxic than chemotherapeutic agents, are usually not approved by the Food and Drug Administration (FDA) and are not



Richard Neubauer, M.D., Ocean Hyperbaric.

part of a recognized or standard cancer treatment protocol. Mr. Jaffe, who has been the lawyer for many high-profile alternative medicine practitioners, including Stanislaw Burzynski, M.D., of the Burzynski Research Institute, Houston, Texas, points out that, when these patients land in the hospital, it is often because of side-effects and complications

from previously administered conventional treatments, such as radiation, and chemotherapy.

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Personal Experiences

I myself have had many personal experiences with the standard of care of hospital life since 1990, when my husband Tim's cancerous brain tumor was first diagnosed. From 1990 to 1995, we followed our doctors' orders fairly closely. For some reason, even without holistic therapies, Tim survived.

Although he did not have a recurrence of his tumor until 2000, Tim began to experience numerous complications: seizures; a stroke; extreme fatigue; et cetera. We hired a nutritionist, Jeanne Wallace, Ph.D., (Nutritional Solutions, Logan, Utah), whose area of greatest experience was nutritional support for people with brain tumors. Once Tim began to eat more nutritious foods and take supplements to improve both immunity and cognition, he started to feel better. I was so grateful and impressed that I vowed that nutrition would be a primary part of his recovery, even if he were to be hospitalized again. Tim agreed.

Then, in 2001, Tim was operated on for tumor recurrence. Because his skin had been radiated in 1990, it was extremely fragile and therefore would not heal. His suture line leaked cranial fluid for nearly 10 months, resulting in numerous severe infections. Tim was hospitalized twice, each time for 4 months. There were several instances when Tim was given incorrect doses of medications and that resulted in his having to be treated in the

intensive care unit. Once, he was given 10 times the prescribed dose of a medication, an event that is called, in hospital circles, “death by decimal.”

When his condition failed to improve, I was no longer permitted to bring him home-made food and the supplements prescribed by his nutritionist.

Thank goodness, he survived. It was during these hospitalizations that I was to learn, first-hand, how dangerous the standard of care could be to Tim’s life and his desire to use alternative medical modalities.

By the time Tim arrived at the second hospital with his suture line leaking again, he had already suffered many brain infections and was becoming increasingly brain-injured. But this hospital had a hyperbaric oxygen chamber and, because his skin was still breaking down, I begged to be allowed to have him treated with HBOT. I naively thought the doctors would agree because one of the common, FDA-approved uses of hyperbaric oxygen is for radionecrosis and nonhealing wounds, both of which were at the crux of Tim’s problem. He was turned down several times. I was told: “All of our patients are outpatients. They are not that sick.”

Terrified, and convinced that Tim would die if his suture line continued to leak cranial fluid, I called Paul Harch, M.D. (Harvey, Louisiana), a professional colleague of Dr. Neubauer’s, and a world-famous expert on hyperbaric oxygen for treating brain injury in his own right. Dr. Harch called the conventional physician who ran the chamber and begged him to allow Tim to be treated. Dr. Harch’s request was also denied.

My husband has been home for 4 years now but he is still severely brain-injured and fatigued as a result of his “treatment” in two U.S. hospitals. When he recovers enough strength, I am planning to take him to Florida for hyperbaric oxygen treatments.

The Future

But what can be done now, so that the next person who suffers brain injury does not get the same backward treatment that was given to Ms. Schiavo, or to Tim?

The good news is that, as a result of the Schiavo case, the word about HBOT is finally “out there” in a big way. A recent search on Google News, using the term hyperbaric, brought up more than 300 hits.

Recently, Dr. Harch was interviewed at length for an article, in the *Toledo Blade*, about the case of a child with cerebral palsy who was treated successfully with HBOT. When I spoke with Dr. Harch, he was very excited about this as-yet-unpublished article; he said he had taken a great deal of time explaining to the writer all about the efficacy of HBOT for brain injury and about the politics surrounding the treatment. How did the article turn out? The executive director of the Undersea and Hyperbaric Medical Society was quoted prominently; Dr. Harch was given one line—near the end of the article—and it had nothing to do with the science of HBOT. But the account of the improvements of the child with cerebral palsy after HBOT stayed in. Perhaps, this is progress.

Is there something practical that ACM practitioners can do now? I have been a public relations consultant for private practitioners for nearly 20 years and I believe the time is right for the

experts in the use of hyperbaric medicine to treat neurologic conditions to make a concentrated effort to educate medical professionals and the public in a concerted and articulate way.

It can be emphasized that we may not have double-blinded clinical trials (they are costly and, in the case of HBOT, would be extremely difficult to do); but we do have hundreds of compelling success stories that could make provocative and effective media presentations, including true accounts of people who have been brought out of comas, strokes, and brain injuries—patients who are now living productive lives and children with cerebral palsy who are now more “normal” as a result of HBOT.

Let HBOT be the first issue for this kind of intense media exposure. First, this information is already “out there”—thanks to the Schiavo case. Second, because of the seriousness of the neurologic conditions not helped by conventional medicine, that may be helped by HBOT. And, third, there are excellent, extremely qualified medical spokespeople, such as Drs. Neubauer and Harch, who can present this important information in the most compelling way.

There is also an organization, MUMS, founded by Julie Gordon, the parent of a child with cerebral palsy. This group has been working hard to get the word out about the benefits of HBOT for cerebral palsy. Ms. Gordon, along with some of her group’s most articulate members, would also be excellent media spokespeople, working together with the physicians.

One person who has trained professionals and businesspeople successfully since 1972 in effective ways to present their stories through the media is Dave Baum (Dave Baum Media Training Group, Skokie, Illinois). Mr. Baum stated that “another situation [like the Schiavo case] will come along, and if alternative practitioners want their opinions to be heard, they [had] better gather up what they want to say now, and learn to explain it in terms anyone with a fourth-grade education to a Ph.D. can easily understand.” He noted that they must communicate the potential of this important therapeutic option, “instead of talking about machines.”

I am reminded of what Dr. Harch said to me: “As the word about HBOT for neurologic conditions gets out to the public and more and more people have been successfully treated, it will be used and endorsed by more practitioners and patients.” He compared HBOT to chiropractic, saying that at one time “conventional doctors in the U.S. were against chiropractic,” and some skepticism still remains. He added:

But there was massive widespread use of, and undeniable satisfaction with, the treatment. Then, against the backdrop of three independent studies by the British, Canadian, and Australian governments on different components of chiropractic, all of them with favorable conclusions, chiropractic finally came into its own [and] insurance companies are covering [such treatments].

Dr. Harch concluded: “I am confident that this will happen with HBOT for neurologic conditions.” Let us hope that he is right. □

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