

The Terri Schiavo saga

Ethical and legal aspects and implications for clinicians

Paul S. Mueller

Division of General Internal Medicine, Mayo Clinic, Rochester, MN, United States

KEY WORDS

ethics, life support care, withholding treatment, enteral nutrition, palliative care

ABSTRACT

On March 31, 2005, Terri Schiavo (born December 3, 1963) died – the final complication of a cardiac arrest on February 25, 1990. Her death was preceded by the withdrawal of artificially administered hydration and nutrition through a feeding tube. Prior to her death, Terri's saga was the focus of intense medical, ethical, and legal debates in the United States (US) and elsewhere. These debates were characterized by confusion about the facts, ethical principles, and laws relevant to the case. Much of the confusion revolved around a number of ethical and legal questions including: Is it ethically and legally permissible to withhold or withdraw life-sustaining treatments from patients who do not want the treatments? Is withholding or withdrawing life-sustaining treatments the same as physician-assisted suicide or euthanasia? Is artificially administered hydration and nutrition a medical treatment or mandatory care akin to bathing? What were Terri's values, preferences, and goals regarding life-sustaining treatments? In this article, the medical, ethical, and legal data related to the case and the aforementioned ethical and legal questions raised by it are reviewed. Finally, the clinical implications of the saga, such as the need for clinicians to be more proactive in educating patients about their rights related to making health care decisions, end-of-life care options, and advance care planning (e.g., completing an advance directive) are discussed. Notably, given that the Schiavo saga occurred in the US, this article is written from a US perspective.

Introduction On March 31, 2005, Terri Schiavo (born December 3, 1963) died – the final complication of a cardiac arrest on February 25, 1990. Her saga was the focus of intense medical, ethical, and legal debates in the United States (US) and elsewhere. These debates were characterized by confusion about the facts, ethical principles, and laws relevant to the case. Much of the confusion revolved around the following questions: Is it ethically and legally permissible to withhold or withdraw life-sustaining treatments from patients who do not want the treatments? Is withholding or withdrawing life-sustaining treatments the same as physician-assisted suicide or euthanasia? Are artificially administered hydration and nutrition medical treatments or mandatory care akin to bathing? What were Terri's values, preferences, and goals regarding life-sustaining treatments should she become seriously ill and unable to make decisions for

herself? Who speaks for the patient when the patient cannot? What are the duties of surrogate decision makers? What should be done if a surrogate is suspected of making decisions that are inconsistent with the patient's health care-related values, preferences, and goals or not acting in the patient's best interest?

Fortunately, a large body of data related to the Schiavo saga is available for review. A very useful website created and maintained by the University of Miami provides a timeline of and links to original reports, judicial decisions, and testimony presented during the court proceedings of the Schiavo saga.¹ In this article, these data and the ethical and legal aspects of the case will be reviewed. In addition, the aforementioned questions will be answered as objectively as possible. Notably, given that the Schiavo saga occurred in the US, this article is written from a US perspective.

Correspondence to:

Paul S. Mueller, MD, MPH, FACP,
Division of General Internal Medicine
and Program in Professionalism
and Bioethics, Mayo Clinic, 200
First Street SW, Rochester, MN
55905, USA,

phone: +1-507-284-0155,

fax: +1-507-284-5889,

e-mail: mueller.pauls@mayo.edu

Received: July 29, 2009.

Accepted: July 29, 2009.

Conflict of interest: Dr. Mueller is
a member of the Boston Scientific
Patient Safety Advisory Board and
is an Associate Editor of *Journal
Watch General Medicine* (neither
of these are relevant to this article).

Pol Arch Med Wewn. 2009;

119 (9): 574-581

Copyright by Medycyna Praktyczna,
Kraków 2009

Key medical facts of the Schiavo saga On February 25, 1990, at the age of 26 years, Terri Schiavo had a cardiac arrest. The cause of the arrest remains unknown.² Despite being resuscitated, Terri developed severe hypoxic-ischemic encephalopathy and never regained consciousness. She was ultimately diagnosed with persistent vegetative state (PVS) characterized by alternating periods of wakefulness and sleep, reflexive responses to light, and gag reflexes. Computed tomography of the head revealed severe brain atrophy and electroencephalography revealed no cortical activity. Numerous treatments and therapy programs failed to restore any cognitive or motor function. Because Terri could not swallow water or food, a percutaneous endoscopic gastrostomy feeding tube was placed to provide hydration and nutrition. Notably, meaningful cognitive or motor recovery 3 months or more after the diagnosis of PVS has been made in a patient, who experiences hypoxic-ischemic encephalopathy, is extremely rare. Indeed, following her cardiac arrest, Terri manifested no meaningful recovery of brain function.³ The police investigation at the time of Terri's cardiac arrest⁴ and the autopsy after her death⁵ revealed no evidence of physical abuse.

Key ethical and legal facts of the Schiavo saga The ethical and legal facts of the Schiavo saga are described in detail elsewhere.^{3,6,7} Thus, only the salient facts will be given here. At the time of her cardiac arrest, Terri Schiavo was married to Michael Schiavo. The courts and the state of Florida accepted the diagnosis of PVS and that Terri lacked decision-making capacity.⁸ According to Florida law, Michael Schiavo was the surrogate health care decision maker for Terri. Additionally, the courts formally appointed Michael as Terri's surrogate decision maker. For several years after Terri's cardiac arrest, her parents, Robert and Mary Schindler, did not dispute Michael's status as Terri's surrogate, and Michael and the Schindlers lived together. Furthermore, the Schindlers encouraged Michael to get on with his life and date other women.⁹ During this time, Michael pursued aggressive treatments for Terri (e.g., physical therapy, occupational therapy, implantation of a thalamic stimulator, etc.).

During 1992, the relationship between Michael and the Schindlers deteriorated. The reasons for this deterioration are unclear (and probably always will be).⁶ Nevertheless, as a result, the Schindlers petitioned the court to remove Michael as Terri's surrogate. Court testimony affirmed that Michael always acted appropriately and in Terri's best interests, and the courts affirmed Michael's status as Terri's surrogate.¹⁰

By 1994, Michael began to believe that Terri would not recover from her PVS. Recalling that, prior to her cardiac arrest, Terri had expressed to others that she would not want to be kept alive artificially should she become seriously ill and if there was no hope for meaningful recovery¹¹, Michael requested that the court authorize

the removal of Terri's feeding tube. The Schindlers disagreed, stating they would continue the feeding tube regardless of Terri's preferences.¹² The courts ruled that "clear and convincing" evidence of Terri's preferences regarding life-sustaining treatments existed (i.e., that she would not want artificially administered hydration and nutrition if she were in a PVS).^{11,13} As a result, hydration and nutrition provided through her feeding tube were stopped for the first time during April 2001. Notably, the courts also affirmed the default position of favoring the preservation of life (and therefore maintaining life-sustaining treatments) in situations in which a patient's wishes are unknown.⁹

Over the next 4 years, numerous petitions, court proceedings, and appeals occurred. All levels of the judiciary were involved; indeed, the District Court of Appeals of Florida, the Florida Supreme Court, and the US Supreme Court were involved in the saga multiple times. All levels of the executive and legislative branches of the Florida and US governments (including the US president and Congress) were also involved. Artificially administered hydration and nutrition using Terri's feeding tube were stopped three times and re-started twice. Ultimately, after all legal appeals were exhausted, Terri Schiavo died on March 31, 2005, about 2 weeks after hydration and nutrition were stopped the third time.

Principles of biomedical ethics Clinical ethics is the identification, analysis, and resolution of moral problems that arise in the care of patients.¹⁴ Four *prima facie* principles characterize most ethical concerns in clinical practice: beneficence, nonmaleficence, respect for patient autonomy, and justice.¹⁵ *Beneficence* refers to the clinician's duty to promote the interests of patients, whereas *nonmaleficence* refers to the duty to prevent or do no harm. *Respect for patient autonomy* refers to the duty to respect patients, their health care-related values, preferences and goals, and their rights of self-determination. *Justice* refers to the duty to treat patients fairly (i.e., based on medical need, not on patient characteristics such as gender, age, or race). In general, no principle has priority over another. However, depending on the circumstances of a given clinical scenario, one principle may take priority over the others. In addition, these principles may be at odds with each other. For example, a clinician's desire to help a patient (e.g., placement of a feeding tube to provide hydration and nutrition) may be at odds with the patient's values, preferences, and goals (e.g., to avoid a treatment perceived as burdensome).

Frequently-asked questions asked during the Schiavo saga **Is it ethically and legally permissible to withhold or withdraw life-sustaining treatments?** From an ethical standpoint, *respect for patient autonomy* is the principle that underlies a patient's right to control what is done to his or her body

including the right to refuse, or request the withdrawal of, an unwanted treatment whether or not the patient is terminally ill, and whether or not the treatment prolongs life (and not using it results in death).¹⁶ Furthermore, patients may decline a treatment to which they previously consented if their health care-related preferences and goals have changed.¹⁷ In the US, there are no ethical or legal differences between withholding or withdrawing treatments, including treatments that are life-sustaining.^{15,18,19} Regardless of intent, it is unethical for a clinician to begin or continue a treatment that a patient has refused. Furthermore, beginning or continuing a treatment that a patient has refused is illegal (constituting battery).²⁰ Notably, no US court has found a clinician liable for wrongful death or murder for granting an informed patient's (or a surrogate's) refusal of, or request to withdraw, a life-sustaining treatment.²¹

From a legal standpoint, a number of US court cases have affirmed a patient's right to refuse, or request the withdrawal of, life-sustaining treatments. In the 1976 *Quinlan*²² case, the New Jersey Supreme Court declared the right to privacy includes the right to refuse unwanted treatments including life-sustaining treatments. In the 1986 *Bowvia*²³ case, the California Court of Appeals declared that competent persons, whether or not they are terminally ill, have the right to refuse life-sustaining treatments including artificially administered hydration and nutrition and that such a refusal is not akin to suicide. The definitive statement in the US, however, was the 1990 US Supreme Court *Cruzan*²⁴ decision. This case involved a patient, Nancy Cruzan, who was in a PVS after an automobile accident and was sustained with artificially administered hydration and nutrition through a feeding tube; Nancy's family, who claimed she would not want such treatment in her current state; and the State of Missouri over whether the feeding tube could be withdrawn. The Missouri Supreme Court declared that clear and convincing evidence of the patient's wishes must be presented before life-sustaining treatments are withheld or withdrawn. The US Supreme Court affirmed that competent patients have the right to refuse unwanted treatments, including artificially administered hydration and nutrition. In fact, the court made no distinction between artificially administered hydration and nutrition and other life-sustaining treatments. The court also affirmed the rights of incompetent persons to refuse life-sustaining treatments through prior statements and surrogate decision makers. However, the court acknowledged that individual states may adopt clear and convincing evidentiary standards for withholding or withdrawing life-sustaining treatments if the patient is incapable of speaking for himself or herself.

Indeed, some states, including Florida²⁵, have a clear and convincing standard²⁶. During the Schiavo saga, which took place in Florida, depositions of members of Terri's family were

presented to the court which recounted statements made by Terri in which she had expressed that she would not want to be maintained on artificial life support should she become seriously ill. As previously noted, the courts ruled that clear and convincing evidence of Terri's preferences regarding life-sustaining treatments existed and that she would not want, given her PVS, long-term artificially administered hydration and nutrition. Notably, in reference to the Schiavo case, 55 bioethicists submitted a brief to a Florida court, which stated: "The implicated bioethical issue is not whether elderly or disabled persons can be deprived of wanted treatment, but how to implement their fundamental right to decline life-prolonging measures they would abhor. It is certainly true...that 'the State has a compelling interest in ensuring that people with disabilities are not deprived of basic human rights' ... but among those basic human rights is the right to refuse medical treatment. The Governor [of Florida] wanted to deprive Terri Schiavo of that right, which the judicial process has determined she would want to exercise."²⁷

Are artificially administered hydration and nutrition medical treatments or mandatory basic care?

This question was raised and debated not only during the Schiavo saga, but also during the *Cruzan* case. From a legal standpoint, the matter was settled with the *Cruzan* decision, in which the US Supreme Court ruled that artificially administered hydration and nutrition are medical treatments. In fact, the court made no distinction between artificially administered hydration and nutrition and other life-sustaining treatments.

From a practical standpoint, there are several reasons why artificially administered hydration and nutrition are medical treatments and not basic care (i.e., care that could have been administered by clinicians before the modern era such as bathing and proper bedding). First, the feeding tube is a relatively new technology that was developed specifically for patients who have pathologies that impair or preclude swallowing. Second, placing a percutaneous endoscopic gastrostomy feeding tube requires endoscopy or a surgical procedure. Third, the nutritional formulas that are infused through a feeding tube must be managed by a nutritionist. Fourth, as with any treatment, patients with feeding tubes can experience complications. In fact, about 10% of patients with percutaneous endoscopic gastrostomy feeding tubes experience complications due to the tube in the long term.^{28,29} Artificially administered hydration and nutrition are no different than other life-sustaining treatments that bypass other pathologies that prevent normal physiological and anatomical functions (e.g., hemodialysis for kidney failure and mechanical ventilation for respiratory failure). Therefore, in the case of Terri Schiavo, the feeding tube that was required to sustain her was beyond the level of basic care, i.e., it was a medical treatment.⁶

From an ethical standpoint, questions about what represents basic yet mandatory care and what represents medical treatment have surfaced throughout the history of medicine, and have been applied to interventions that today we clearly regard as medical treatments (e.g., hemodialysis and mechanical ventilation). Beneficial as they may be, medical treatments are foreign to the body as evidenced by the fact that most people get along well without the treatment until they become ill or injured. It is wrong to insist that specific medical treatments, such as artificially administered hydration and nutrition, be mandatory; when we do “medicine becomes less a servant of humankind and more a master”.⁶

Nevertheless, many people object to denying patients hydration and nutrition. In the US, such values are respected. Had it been discovered that Terri Schiavo wanted artificial life support, her wish would have been respected. If her preferences had remained unknown, life support (i.e., the artificially administered hydration and nutrition) would have been continued. Indeed, in cases of doubt, US courts assume that patients would choose to be kept alive in exercising their rights to privacy. In fact, a judge during the Schiavo saga declared, “We confirm today that a court’s default position must favor life.”⁹ Clinicians should ensure that patients and their loved ones understand the risks, benefits, and alternatives to life-sustaining treatments and especially the differences between water and food consumed by those who are able to eat and drink, and hydration and nutrition administered through a feeding tube. Patients should be encouraged to express verbally their values, preferences, and goals regarding life-sustaining treatments to their loved ones and clinicians and in writing as part of an advance directive (see below).

Is terminal dehydration painful? Inaccurate descriptions of the consequences of withdrawing artificially administered hydration and nutrition circulated during the Schiavo saga. For example, on the floor of the US House of Representatives, Representative Joe Pitts, declared: “Mr. Speaker, death by dehydration is a painful, agonizing, and arduous process...In addition to feeling pangs of hunger and thirst, the skin, lips, and tongue crack, the nose bleeds because of the drying of mucous membranes, heaving and vomiting may ensue because of the drying out of the stomach lining, and the victim may experience seizures. Compared to starvation and dehydration, death by hanging, firing squad, or even the electric chair seems humane.”³⁰

Representative Pitts’ statement is untrue. Prior research has shown that most patients do not experience significant thirst when artificially administered hydration is discontinued, and if they do, these symptoms are easily alleviated with simple local measures.³¹ Patients who forgo artificially administered hydration usually experience

comfortable deaths.^{32,33} Also, artificially administered hydration does not necessarily relieve thirst in alert terminally ill patients.³⁴ However, withholding or withdrawing artificially administered hydration, or any life-sustaining treatment, does not mean that good palliative care, i.e., bathing, symptom control, and other comfort measures, should also be withheld. Rather, scrupulous attention to palliative care *is* mandatory.

Is withholding or withdrawing artificially administered hydration and nutrition the same as assisted suicide and euthanasia? Another claim made during the Schiavo saga was that withdrawing Terri’s feeding tube was akin to physician-assisted suicide and euthanasia. From an ethical standpoint, this claim is inaccurate. In physician-assisted suicide, the patient personally terminates his or her life using a means provided by a clinician (e.g., lethal prescription). In euthanasia, the clinician terminates the patient’s life (e.g., lethal injection). In physician-assisted suicide and euthanasia, a new pathology is introduced (e.g., drugs), the intent of which is death of the patient. In contrast, when a patient dies after withholding or withdrawing a treatment, the cause of death is the underlying pathology (e.g., disease or injury); a new pathology is not introduced. The intent of withholding or withdrawing a treatment is freedom from a treatment that is perceived as burdensome.^{16,35,36} For example, when a patient with kidney failure dies after refusing hemodialysis, a life-sustaining treatment, the cause of death is kidney failure, not the treatment refusal. Likewise, when a patient with respiratory failure dies after withdrawal of mechanical ventilation, the cause of death is respiratory failure, not the treatment withdrawal.

In the case of Terri Schiavo, her underlying pathology (PVS and resultant inability to swallow water and food), not the withdrawal of the feeding tube, was the cause of her death. While the decision to withhold or withdraw a life-sustaining treatment may lead to death, it differs from a decision to pursue physician-assisted suicide or euthanasia. On one hand, refusing or withdrawing life-sustaining treatments is a request to avoid unwanted treatments and to die naturally. As discussed previously, *respect for patient autonomy* is the ethical principle that underlies a patient’s right to control what is done to his or her body including the right to refuse, or request the withdrawal of, unwanted treatments. On the other hand, physician-assisted suicide and euthanasia are deliberate acts in which a person, not a pathological condition, is the final arbiter of death.⁶

Notably, in the 1997 *Vacco v Quill* decision, the US Supreme Court made a clear distinction between withholding or withdrawing unwanted treatments and euthanasia: “The distinction comports with fundamental legal principles of causation and intent. First, when a patient refuses life-sustaining medical treatment, he dies from an underlying fatal disease or pathology; but

if a patient ingests lethal medication prescribed by a physician, he is killed by that medication... [In Cruzan] our assumption of a right to refuse treatment was grounded not...on the proposition that patients have a general and abstract 'right to hasten death', but on well established [sic], traditional rights to bodily integrity and freedom from unwanted touching."³⁷

In other words, it is not that people in the US have a "right to die", but rather people have a right to be left alone. While two US states, Oregon and Washington, have legalized physician-assisted suicide, euthanasia is illegal throughout the US. In addition, neither the American College of Physicians¹⁹ nor the American Medical Association³⁸ endorses physician-assisted suicide and euthanasia.

Who speaks for the patient when the patient cannot? Clinicians frequently care for patients with impaired decision-making capacity.³⁹ In these situations, physicians must rely on surrogates to make decisions for the patient. The ideal surrogate is the person who best understands the patient's health care-related values, preferences, and goals⁴⁰; this person may or may not be a family member. In the US, adults have the right to complete an advance directive (AD) – written instructions for future health care if the patient lacks decision-making capacity, which might include designating a surrogate decision maker.

In general, there are three forms of ADs: the durable power of attorney for health care, the living will, and the combined AD which has features of both a power of attorney and living will.⁴¹ The durable power of attorney allows the patient to designate a surrogate. The living will allows the patient to list treatments and other actions that should or should not be implemented in specific circumstances (e.g., terminal illness). All 50 states and the District of Columbia in the US have laws that recognize ADs as an extension of patient autonomy for preserving patient autonomy when patients lack decision-making capacity.²⁶ Furthermore, the Patient Self-Determination Act, a federal law, requires that health care institutions ask patients whether they have an AD, inform patients of their right to complete an AD, and incorporate patients' ADs into their medical records.⁴²

Unfortunately, most Americans do not have ADs.³⁹ Likewise, Terri Schiavo did not have an AD. In these situations, clinicians must identify a surrogate decision maker. Many states have laws that specify a hierarchy of surrogates (e.g., court-appointed surrogate, followed by the spouse, adult child, and so on). Terri Schiavo lived in Florida, which has a specific hierarchy for establishing a surrogate in the absence of an AD; the relevant Florida law states, "If an incapacitated...patient has not executed an advance directive, or designated a surrogate to execute an advance directive...health care decisions may be made for the patient by any of the following individuals,

in the following order of priority: 1) judicially appointed surrogate, 2) the patient's spouse, 3) an adult child of the patient, or majority of adult children, 4) a parent of the patient, 5) an adult sibling, or majority of adult siblings, 6) an adult relative, or 7) a close friend of the patient."⁴³

During the Schiavo saga, Michael not only was Terri's court-appointed surrogate, but also her spouse – the two highest ranking positions for selecting a surrogate by law in Florida – which accounts for why he was Terri's surrogate decision maker throughout the saga.

What are the duties of a surrogate decision maker?

The ethical principle of *respect for patient autonomy* requires that a surrogate follow instructions in the patient's AD, if one exists. In the absence of an AD, a surrogate must use "substituted judgment", i.e., make decisions as closely as possible to those the patient would make if capable. In order to achieve substituted judgment, a useful question to ask a surrogate is, "If the patient could wake up for 15 minutes and understand his or her condition fully, and then had to return to it, what would he or she tell you to do?"³ Nevertheless, surrogates may not know how the patient would decide. In these situations, the surrogate must use the "best interest" standard, i.e., given the medical facts and prognosis, make decisions that would be in the best interests of the patient.

Notably, Florida law also states, "Before exercising that incapacitated patient's rights to select or decline health care,...the surrogate's decision to withhold or withdraw life-prolonging procedures must be supported by clear and convincing evidence that the decision would have been the one the patient would have chosen had the patient been competent or, if there is no indication of what the patient would have chosen, that the decision is in the patient's best interest."⁴³ Terri's parents, the Schindlers, testified during court proceedings that, if they were to act as Terri's surrogate decision maker, they would insist on maintaining the feeding tube even if Terri had left written instructions to the contrary.¹² Hence, ethically and legally, they disqualified themselves from being Terri's surrogate decision makers.

What should be done if it is suspected that a surrogate is not acting in the best interests of the patient?

While surrogates have the authority to make decisions for patients, the ethical principle of *beneficence* requires that physicians act on behalf of their patients. If it appears that a surrogate is making decisions that are inconsistent with the previously expressed health care-related values, preferences, and goals of the patient or is making decisions that are not in the best interests of the patient, then the physician should act to protect the patient and, if necessary, seek a court-ordered change of the surrogate.⁶ During the Schiavo saga, Terri's parents, the Schindlers, questioned the appropriateness of Michael as

TABLE Precedence established by landmark cases in the United States concerning the withholding and withdrawing of life-sustaining treatments

The competent patient has the right to refuse or request the withdrawal of life-sustaining treatments regardless if the patient is terminally ill.
The incompetent patient has the same right (as exercised through a surrogate decision maker).
Ethically and legally, there are no differences between withholding life-sustaining treatments and withdrawing life-sustaining treatments.
Withholding and withdrawing life-sustaining treatments are not the same as physician-assisted suicide and euthanasia.
The right to refuse or request the withdrawal of life-sustaining treatments is not a “right to die”, but rather a right to be left alone.
No clinician has been held liable for wrongful death or murder for granting an informed patient’s request to withhold or withdraw life-sustaining treatments.
Artificially administered hydration and nutrition are medical treatments, not mandatory care.

her surrogate and sought court-ordered removal of him as her surrogate. However, the courts consistently found that Michael acted properly as Terri’s surrogate in that he reflected her previously expressed wishes and views about life-sustaining treatments and acted in her best interests.¹⁰

Competing ethical frameworks during the Schiavo saga The guiding ethical principle throughout the Schiavo saga was *respect for patient autonomy*. Nevertheless, other ethical frameworks were invoked during the saga. For example, some argued the Schiavo saga was essentially a “sanctity of life” vs. “quality of life” debate. However, “unless one adopts the position that sheer biological existence is what is sacred about human life, considerations of sanctity inevitably involve judgments of quality”.⁷ Furthermore, whose “sanctity” and whose “quality”? In the US, the answer to this question is “the patient”. The ethical principle of *respect for patient autonomy*, US law, and the court decisions during the Schiavo saga affirm the prerogative of patients to make decisions about medical treatments according to their own health care-related values, preferences, and goals.

Another concern expressed during the Schiavo saga was that withdrawing artificially administered hydration and nutrition from Terri would result in widespread disregard of persons with disabilities and others judged to have poor quality of life. However, “the wisdom of deciding this case within the moral framework of individual autonomy...is that it portends nothing as a general policy...” for persons with disabilities.⁷ Indeed, the outcome of Schiavo saga affirmed the primacy of the individual patient’s values, preferences, and goals in health care decision making.

Conclusions and implications for clinicians The Terri Schiavo saga was a tragedy. Ultimately, however, the medical, ethical, legal, and social facts of the case are clear. Throughout the saga, the courts carefully considered all of the claims made by Terri’s husband and her parents, evidence regarding Terri’s preferences and goals for artificial life-sustaining treatments, and relevant US

laws. Indeed, according to one review of the case: “In our opinion, the law did not fail Terri Schiavo. In fact, no end-of-life guardianship case in US history has generated as much high-quality evidence, judicial attention, or legal scrutiny as the Terri Schiavo case. Throughout a lengthy trial and evidentiary hearing, countless motions, oral arguments, and numerous appeals to every available state and federal court, this case shows that the judicial process works at the end of life.”⁷

The courts based their decisions on Terri’s previously expressed wishes, not on judgments on the value of her life. Indeed, the final outcome of the Schiavo saga – her death following withdrawal of artificially administered hydration and nutrition, a treatment she did not want – is consistent with precedence established by similar cases in the US (TABLE).

There are a number of lessons to be learned from the Schiavo saga. First, clinicians and the broader health care community should be more proactive in educating patients about their rights related to making health care decisions, particularly those outlined in this article (e.g., the right to refuse and request the withdrawal of unwanted treatments, the right to engage in advance care planning by completing an AD, end-of-life care options, etc.). Clinicians should encourage patients to discuss end-of-life values, preferences, and goals. Patients should be encouraged to engage in advance care planning by expressing their values, preferences, and goals verbally to their clinicians and loved ones and in writing by completing ADs. Notably, in the US, patients’ interest in advance care planning increased during and after the Schiavo saga and Terri’s death.⁴⁴ Clinicians should review patients’ ADs and ensure that they reflect patients’ values, preferences, and goals. When patients refuse or request the withdrawal of treatments, clinicians should ensure that these refusals or requests are informed. Clinicians should encourage public discussion of end-of-life issues and should oppose policies that mandate medical treatments for patients who might not want them. Finally, clinicians and society should value and reassure our disabled communities.

Acknowledgments The author is indebted to C. Christopher Hook, MD for his valuable input into this article.

REFERENCES

- 1 Cerminara K, Goodman K. Key events in the case of Theresa Marie Schiavo. Available at: <http://www6.miami.edu/ethics/schiavo/timeline.htm>. Accessibility verified July 26, 2009.
- 2 Thogmartin JR. Report of autopsy. Available at: http://www6.miami.edu/ethics/schiavo/pdf_files/061505-autopsy.pdf. Accessibility verified July 26, 2009.
- 3 Quill TE. Terri Schiavo – a tragedy compounded. *New Engl J Med*. 352; 16: 1630-1633.
- 4 St Petersburg Police Department incident report. Available at: http://www6.miami.edu/ethics/schiavo/pdf_files/022590_police_report.pdf. Accessibility verified July 26, 2009.
- 5 Crow D, Lewis B. Memo to State Attorney Bernie McCabe from prosecutors Doug Crow and Bob Lewis. Available at: <http://www6.miami.edu/>

- ethics/schiavo/pdf_files/070705-Crow-Lewis-to-McCabe.pdf. Accessibility verified July 26, 2009.
- 6 Hook CC, Mueller PS. The Terri Schiavo saga: the making of a tragedy and lessons learned. *Mayo Clin Proc.* 2005; 80: 1449-1460.
 - 7 Perry JE, Churchill LR, Kirshner HS. The Terri Schiavo case: legal, ethical, and medical perspectives. *Ann Intern Med.* 2005; 143: 744-748.
 - 8 Florida Governor's Office. Executive order Number 03-201. Available at: http://www6.miami.edu/ethics/schiavo/Schiavo_Controversy_Fla_Gov_Exec_Order_No_03-201.html. Accessibility verified July 26, 2009.
 - 9 Wolfson J. A report to Governor Jeb Bush in the matter of Theresa Marie Schiavo, December 1, 2003. Available at: http://www6.miami.edu/ethics/schiavo/pdf_files/wolfson's_report.pdf. Accessibility verified July 26, 2009.
 - 10 Copeland L, Lawrence J. Feud may be as much over money as principle. *USA Today.* March 24, 2005. Available at: www.usatoday.com/news/nation/2005-03-24-schiavo-money-cover_x.htm. Accessibility verified July 26, 2009.
 - 11 In re: the guardianship of Theresa Marie Schiavo, incapacitated. File No.90-2908GD-003. February 11, 2000: p. 9. Available at: http://www6.miami.edu/ethics/schiavo/pdf_files/021100-Trial_Ct_Order_0200.pdf. Accessibility verified July 26, 2009.
 - 12 Excerpt of trial testimony of Father Murphy. Available at: <http://www6.miami.edu/ethics/schiavo/timeline.htm>. Accessibility verified July 26, 2009.
 - 13 In re: guardianship of Theresa Marie Schiavo, incapacitated. Case No.2D00-1269. January 24, 2001: pp 7-9. Available at: http://www6.miami.edu/ethics/schiavo/pdf_files/1-24-01_DCA_Opinion.pdf. Accessibility verified July 26, 2009.
 - 14 Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 6th ed. McGraw-Hill, 2006.
 - 15 Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*, 5th ed. Oxford University Press, 2001.
 - 16 Mueller PS, Hook CC, Fleming KC. Ethical issues in geriatrics: a guide for clinicians. *Mayo Clin Proc.* 2004; 79: 554-562.
 - 17 Quill TE, Barold S, Sussman BL. Discontinuing an implantable cardioverter defibrillator as a life-sustaining treatment. *Am J Cardiol.* 1994; 74: 205-207.
 - 18 Meisel A, Kuczewski M. Legal and ethical myths about informed consent. *Arch Intern Med.* 1996; 156: 2521-2526.
 - 19 Snyder L, Leffler C, Ethics and Human Rights Committee, American College of Physicians. *Ethics manual.* *Ann Intern Med.* 2005; 142: 560-582.
 - 20 *Schloendorff v Society of New York Hospital*, 211 NY 125, 129-30, 105 NE 92, 93 (1914).
 - 21 Gostin LO. Deciding life and death in the courtroom: from Quinlan to Cruzan, Glucksberg, and Vacco - a brief history and analysis of constitutional protection of the "right to die." *JAMA.* 1997; 278: 1523-1528.
 - 22 In re: Quinlan, 355 A2d 647 (NJ), cert denied, 429 US 922 (1976).
 - 23 *Bouvia v Superior Court*, 179 Cal App 3d 1127, at 1146-47, 225 Cal Rptr 297 (1986).
 - 24 *Cruzan v Director, Missouri Dept of Health*, 497 US 261 (1990).
 - 25 In re: Guardianship of Browning, 568 So 2nd 4, 10 (Fla 1990).
 - 26 Gillick MR. Advance care planning. *N Engl J Med.* 2004; 350: 7-8.
 - 27 Amicus curiae brief in support of Michael Schiavo as guardian of the person of Theresa Marie Schiavo (filed with the consent of the parties). Available at: <http://www.law.fsu.edu/library/flsupct/sc04-925/04-925ac55bioethicists.pdf>. Accessibility verified July 26, 2009.
 - 28 Rabeneck L, Wray NP, Petersen NJ. Long-term outcomes of patients receiving percutaneous endoscopic gastrostomy tubes. *J Gen Intern Med.* 1996; 11: 287-293.
 - 29 Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA.* 1999; 282: 1365-1370.
 - 30 Starvation is an inhumane way to die. *Congressional Record - House.* H9741 (October 21, 2003). http://ftp.resource.org/gpo.gov/record/2003/2003_H09741.pdf. Accessibility verified July 26, 2009.
 - 31 McCann RM, Hall WJ, Groth-Juncker A. Comfort care for terminally ill patients: the appropriate use of nutrition and hydration. *JAMA.* 1994; 272: 1263-1266.
 - 32 Ganzini L, Goy ER, Miller LL, et al. Nurses' experiences with hospice patients who refuse food and fluids to hasten death. *N Engl J Med.* 2003; 349: 359-365.
 - 33 Pasman HR, Onwuteaka-Philipsen BD, Kriegsman DM, et al. Discomfort in nursing home patients with severe dementia in whom artificial nutrition and hydration is forgone. *Arch Intern Med.* 2005; 165: 1729-1735.
 - 34 Ellershaw JE, Sutcliffe JM, Saunders CM. Dehydration and the dying patient. *J Pain Symptom Manage.* 1995; 10: 192-197.
 - 35 Rhymes JA, McCullough LB, Luchi RJ, et al. Withdrawing very low-burden interventions in chronically ill patients. *JAMA.* 2000; 283: 1061-1063.
 - 36 Meisel A, Snyder L, Quill T, American College of Physicians-American Society of Internal Medicine End-of-Life Care Consensus Panel. Seven legal barriers to end-of-life care: myths, realities, and grains of truth. *JAMA.* 2000; 284: 2495-2501.
 - 37 *Vacco v Quill*, 521 US 793 (1997).
 - 38 American Medical Association, Council on Ethical and Judicial Affairs. *Code of Medical Ethics: Current Opinions with Annotations, 2008-2009 ed.* Chicago: American Medical Association; 2008.
 - 39 Hanson LC, Rodgman E. The use of living wills at the end of life: a national study. *Arch Intern Med.* 1996; 156: 1018-1022.
 - 40 Hayley DC, Cassel CK, Snyder L, Rudberg MA. Ethical and legal issues in nursing home care. *Arch Intern Med.* 1996; 156: 249-256.
 - 41 Nishimura A, Mueller PS, Evenson LK, et al. Patients who complete advance directives and what they prefer. *Mayo Clin Proc.* 2007; 82: 1480-1486.
 - 42 Omnibus Budget Reconciliation Act of 1990 (OBRA-90) (Patient Self-Determination Act of 1990). Pub L 101-508, 4206 and 4751 (Medicare and Medicaid, respectively), 42 USC 1395cc(a) (1)(Q), 1395 mm (c)(8), 1395cc(f), 1396a(a)(5)(7), 1396a(a)(5)(8), and 1396a(w) (Supp 1991).
 - 43 Florida Senate. The 2008 Florida Statutes: chapter 765. Available at: http://www.flsenate.gov/statutes/index.cfm?App_mode=Display_Statute&URL=Ch0765/tit0765.htm. Accessibility verified July 26, 2009.
 - 44 Sudore RL, Landefeld CS, Pantilat SZ, et al. Reach and impact of a mass media event among vulnerable patients: the Terri Schiavo story. *J Gen Intern Med.* 2008; 23: 1854-1857.

Historia Terri Schiavo

Aspekty etyczne i prawne oraz wnioski dla lekarzy

Paul S. Mueller

Division of General Internal Medicine, Mayo Clinic, Rochester, MN, Stany Zjednoczone

SŁOWA KLUCZOWE

etyka, opieka paliatywna, terapia przedłużająca życie, wstrzymanie leczenia, żywienie dojelitowe

STRESZCZENIE

31 marca 2005 roku zmarła Terri Schiavo (ur. 3 grudnia 1963 r.). Jej śmierć była ostatecznym następstwem zatrzymania czynności serca dnia 25 lutego 1990 roku. Do zgonu doprowadziło odłączenie aparatury podającej Terri pokarm i płyny. Na długo przed śmiercią kobiety jej sprawa była przedmiotem żywych sporów o kwestie medyczne, etyczne i prawne, nie tylko w Stanach Zjednoczonych. Sporom tym towarzyszyło zamieszanie co do faktów oraz zasad etycznych i prawnych, do których należało się w tym przypadku odwoływać. Spory w dużej mierze dotyczyły szeregu wątpliwości natury etycznej i prawnej: Czy wstrzymanie lub rezygnacja z terapii podtrzymującej życie pacjenta, który nie życzy sobie terapii, jest dopuszczalne z punktu widzenia etyki i prawa? Czy wstrzymanie lub rezygnacja z terapii podtrzymującej życie są równoznaczne z samobójstwem przy pomocy lekarza lub eutanazją? Czy sztuczne nawadnianie i odżywianie należy uznać za rodzaj leczenia, czy też za obowiązkową opiekę (na równi z np. myciem pacjenta)? Czy wartości wyznawane przez Terri, jej preferencje i cele dopuszczałyby rezygnację z terapii podtrzymującej życie? Autor niniejszego artykułu przedstawia fakty medyczne, etyczne i prawne mające związek ze sprawą Terri Schiavo, oraz podejmuje próbę odpowiedzi na przytoczone wyżej pytania. W artykule zostały omówione także wnioski płynące z historii Terri Schiavo, w tym potrzeba bardziej aktywnego informowania przez lekarzy pacjentów o ich prawach do podejmowania decyzji w sprawach opieki medycznej, opieki u schyłku życia oraz planowania postępowania w stanie terminalnym (np. sporządzania oświadczenia woli). Należy zauważyć, że historia Schiavo zdarzyła się w Stanach Zjednoczonych, dlatego niniejszy artykuł został napisany z perspektywy amerykańskiej.

Adres do korespondencji:

Paul S. Mueller, MD, MPH, FACP,
Division of General Internal Medicine
and Program in Professionalism
and Bioethics, Mayo Clinic, 200
First Street SW, Rochester, MN
55905, USA,

tel.: + 1-507-284-0155,

fax: + 1-507-284-5889,

e-mail: mueller.pauls@mayo.edu

Praca wpłynęła: 29.07.2009.

Przyjęta do druku: 29.07.2009.

Zgłoszono sprzeczność interesów:

Dr. Mueller jest członkiem Boston Scientific Patient Safety Advisory Board oraz zastępcą redaktora naczelnego czasopisma *Journal Watch General Medicine* (fakt ten nie miał wpływu na zawartość niniejszego artykułu).

Pol Arch Med Wewn. 2009;

119 (9): 574-581

Copyright by Medycyna Praktyczna,

Kraków 2009