A MEDICAL ETHICS ASSESSMENT OF THE CASE OF TERRI SCHIAVO

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The social, legal, and political discussion about the decision to stop feeding and hydration for Terri Schiavo lacked a medical ethics assessment. The authors used the principles of medical indications, quality of life, patient preference, and contextual features as a guide to medical decision-making in this case. Their conclusions include the following: (a) the use of a feeding tube inserted directly into the stomach constituted artificial treatment; (b) the treatment prolonged biological life but did not lead to a cure and did not restore health; (c) quality of life was absent for the patient, with no sensation and no motor or cognitive functioning; and (d) by preponderance of medical opinion, she would have chosen not to live in a persistent vegetative state. The authors find the withdrawal of treatment was permissible and correct. It was not a choice between living and dying, but a decision of when to allow dying consistent with the patient’s choice.

The case of Terri Schiavo, vexing as it was, holds lessons for us all. The forceful public reactions to the medical and legal proceedings leading to her demise showed a deep schism over the moral/religious issues inherent in how we die in the modern age of medicine. In our opinion, the political and legal wrangling detracted from the public understanding of the medical and bioethical issues involved in the case.

Some might further argue that the case exposed a severe fault line in the bioethics approach to issues of this sort, or at least a limitation of the usefulness of bioethics. After all, the case never went under the scrutiny of a bioethics committee and there was no

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formal statement of medical ethics conveyed to the public in support of letting Terri die. The public media presentation of the case was in social, political, and legal terms, with sparse, if any, discussion of how bioethical principles might apply to the difficult issues involved. The absence of a classic medical ethics assessment was a lost opportunity to educate the public.

In this article we apply the basic tenets of medical ethics to the medical decision-making process in the Schiavo case. Medical ethics, or bioethics, began as a means of giving physicians and other health care providers guidelines for handling ethical problems that occur in the practice of medicine. It then developed as a method for dealing with new ethical issues, particularly those arising from procedures such as artificial kidney treatment (dialysis), resuscitation, and withdrawal of life-sustaining treatment (Jonsen, Siegler, & Winslade, 1992). We use the technique of Jonsen, Siegler, and Winslade (2002), which focuses on four topics clinicians should take into account in assessing the ethical aspects of a medical decision: medical indications, patient preference, quality of life, and contextual features.

Medical Indications

Medical ethics begins by asking whether the proposed treatment or procedure is medically indicated—does it fulfill the goals of medicine? Using the principle of beneficence, we ask does this treatment maintain life, restore health, and prevent symptoms? Do the benefits outweigh the potential harm of the treatment?

What were the medical “facts” of the Terri Schiavo case, and what can bioethics teach us about how to proceed when a next similar case occurs? Removing Terri Schiavo’s feeding tube was not a treatment per se, but rather the discontinuation of treatment with hydration and nutrition. Terri did not sense food in her mouth and did not have a swallowing reflex. Because she was unable to swallow, she could not be fed through her mouth without a strong likelihood of choking to death, so the feeding tube was the only means of keeping her alive. The treatment under analysis is therefore the continuation of fluids and nutrients through Terri’s feeding tube. The central question was whether continued treatment with the feeding tube was medically indicated. Was this treatment of
benefit to Terri, or was the treatment disproportionately burdensome and harmful to her?

One of the goals of medicine is to maintain life or to prevent death. The goal, however, is not to prevent all death but to prevent untimely or inappropriate death. In this case, continued feeding certainly would have kept Terri alive, as it had done for 15 years. Although in many cases the goal of maintaining life is pre-eminent, when the ethical issue is whether life should continue or be allowed to end, this goal is subsumed under other considerations. Whether death from stopping the treatment would have been considered timely or untimely depends on factors such as perceived patient preference, judgment of what would be best for her, and opinions about the quality of her life.

Would continued treatment have relieved symptoms of pain and suffering? No. Terri had only involuntary reflexes, with no function above the brain stem. She had no cognitive function or awareness of her surroundings, and no physical or mental sensation of pain or suffering. Therefore treatment was not relieving suffering.

Would continued treatment have restored health? Would it have cured the disease or improved functional status? Two neurologists selected by Terri’s parents (who opposed ending treatment) suggested that Terri’s smiles and movements represented cognition and sensation, whereas two neurologists selected by Terri’s husband and one selected independently by the court testified that Terri’s reflexes were involuntary and she was in a persistent vegetative state from which she would never recover (see Cerminara’s introductory article for a detailed review of the related history). All five neurologists agreed that Terri had suffered enormous damage to her brain, such that most of her cerebral cortex, which controls conscious thought, was gone, replaced by spinal fluid. The biological probability for a cure of her condition was so minimal as to be effectively zero.

In the second trial, the court heard conflicting evidence as to whether new therapy might succeed in restoring Terri’s brain function and found no credible evidence that Terri would ever recover significant function. This finding was unanimously upheld on appeal. Undeniably, the prognosis in this case was crucial to a sound ethical judgment, and any disagreement makes the decision difficult. We agree with the trial courts that claims of potential improvement with new therapies were without merit. The treatment...
offered no chance for restoring health. Because treatment was not relieving symptoms, and it held no reasonable chance for a cure or clinical improvement, there was no medical indication for continued treatment with the feeding tube.

Germane to the discussion is a related question: Was Terri Schiavo on life support, or was she merely being fed through a tube? Some argued that treatment with food and fluids should never be withdrawn from dying or permanently unconscious patients (e.g., Pope John Paul II, 2004). Feeding is natural, they said, and “merely being fed through a tube” is not life support—it is different from stopping treatments such as artificial breathing with a mechanical ventilator.

We all understand the emotion behind this argument when it is made to keep a loved one alive, but from a medical ethics perspective it is not correct. Medically, stopping feeding is no different from stopping a breathing machine that is keeping someone alive. Air is also natural, and breathing is a natural function. Food and air are equally natural and essential to life. If a person is permanently unable to breathe, we can delay death with artificial breathing. If a person is permanently unable to swallow we can delay death by placing a feeding tube into the stomach and bypassing the need to swallow.

It is as unnatural to pierce through the abdomen and place a tube into a patient’s stomach, and then pour food through the tube or pump it into the stomach with a machine, as it is to use a machine to blow air into a patient’s lungs. With artificial breathing, the air at least goes in and out through the natural wind-pipe, while artificial feeding bypasses the natural process of swallowing food through the esophagus to the stomach. The mechanisms of artificial feeding and breathing are different, but one is not more or less natural than the other.

But, some argued, food and fluids are ordinary and natural and stopping them is “killing,” it is “starving” a person to death (e.g., Pope John Paul II, 2004). On the other hand, they said, it is allowable to disconnect a patient from a breathing machine because it is an extraordinary medical measure (see also, President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). But one is not extraordinary, whereas the other is ordinary. In its landmark report, the President’s Commission for the Study of Ethical Problems in
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Medicine concluded: “There is no basis for holding that whether a treatment is common or unusual, or whether it is simple or complex, is in itself significant to a moral analysis of whether a treatment is warranted or obligatory” (p. 87). Also, according to Florida statute, a “Life-prolonging procedure means any medical procedure, treatment, or intervention, including artificially provided sustenance and hydration, which sustains, restores, or supplants a spontaneous vital function” (Health Care Advance Directives, Definitions, §765.101, 2004, emphasis added; see also §§765.301-309). This is consistent with medical understanding and the tenets of medical ethics. Terri Schiavo was on life-support because she could not survive without the fluid and nutrition treatment she was receiving.

Nonmaleficence

Application of the principle of nonmaleficence (do no harm) leads us to ask, would continued feeding have been good treatment for Terri, or would it have harmed her? Would either maintaining or discontinuing the treatment cause harm out of proportion to benefit for her?

Would removing Terri’s feeding tube be inhumane by causing “starvation” and pain? In comparison to withdrawing artificial breathing with a ventilator, stopping tube-feeding appears to be a long, drawn-out procedure during which the patient may suffer. But Terri had no sensation of thirst or hunger. She did not suffer when the feeding tube was withdrawn, and the absence of food and fluids did not cause suffering (Multi-Society Task Force on PVS, 1994).

There is an important emotional difference between slow dying after withdrawal of food and water and the rapid death following disconnecting a patient from a respirator. One watches the patient dying slowly from absence of food and water and might conclude, “They are starving her to death.” But families do not usually watch their loved one being disconnected from a breathing machine. If they did, they would say, “They are suffocating him to death.” Discomfort or pain is possible in the latter procedure only if the patient is not given sufficient sedative or pain medicine to obliterate symptoms. On the other hand, there is no discomfort associated with dehydration after withdrawal of a feeding tube in a patient with persistent vegetative state.
Would continued treatment have harmed Terri? Unfortunately, many relatives or loved ones of patients on life-supporting therapy do not understand the consequences of continued treatment. Although Terri would not have perceived suffering had she remained alive, over the years or decades to come she inevitably would have acquired illnesses associated with aging and being bed-ridden, which would have increased the psychological burden on her family.

The larger question was whether Terri benefited or was harmed by dying. The answer to this rests in part on her quality of life if feeding had been continued. Certainty on this point is impossible and must take into account the complexity of the judgment of the value of living indefinitely in a persistent vegetative state. Whether Terri benefited or was harmed by dying also depends on determination of her personal preference, or her valuation of continued living in that condition.

**Autonomy, or Patient Preferences**

In our opinion, this is probably the most important ethical determinant of the case. There is little question that had Terri had an advance directive with a clear statement on whether she would want to continue living in a persistent vegetative state, the medical decision would have been according to her stated desire and there would have been little or no controversy. Perhaps the most daunting problem in medical ethics is a life or death decision when the patient cannot state her choice, and the patient’s loved ones have conflicting wishes of what to do. This brings us to the concept of substituted judgment wherein the individual(s) who speaks for the patient must make decisions according to the beliefs and lifestyle of the patient. The judgment should reflect not what the loved ones would want for the patient, but what the patient would want.

Should we consider a patient’s known religious or social beliefs? Indeed, we give much weight to any known such beliefs or affirmations as indicative of a person’s fundamental values and wishes. To this end, an explicit understanding of Terri’s religious or social beliefs, such as from recorded statements, would have helped in determining whether she would have wanted treatment to be continued or stopped. There was nothing conclusive on this point.
We believe no one can be absolutely certain what Terri would have wanted, or how much thought she gave before her injury to what would have been for her a remote and hypothetical matter. Lacking explicit evidence, we cannot gainsay the findings of the courts. By the best evidence we have, Terri Schiavo would not have wished to continue living in the condition of persistent vegetative state (see Cerminara’s introduction).

Autonomy is exceedingly important in medical ethics, and ordinarily trumps the wishes of others. The person involved in the proposed procedure or treatment should in most cases be able to make medical decisions for herself, or, as in this case, through a surrogate or guardian.

But autonomy cannot be absolute if a medical decision hurts others disproportionately to the gain of the person making the autonomous decision. In this case, the decision should take into account the preferences of others, notably Terri’s closest relatives or loved ones. However, the disagreement between Terri’s parents and her husband meant that the wishes of the two sides of the dispute were diametrically opposed. If we give equal weight to the opposing parties, this consideration is a net sum zero, leaving the patient’s desire as the sole determinant. Although some disagree with the determination of what Terri would have wanted, it is based on the best evidence possible, and to go against the best evidence would be unwise.

Quality of Life

Future quality of life assessment is contingent on accurate prognosis. The finding that with continued treatment Terri would have remained indefinitely in a persistent vegetative state means there was no reasonable hope for a cure, awareness of sensation, the ability to move voluntarily, or to have cognitive function. With no awareness, she had no quality of life. Therefore, continued treatment would not have changed her quality of life status—it would not have made it better or worse.

Whether continuing with no quality of life would be seen as favorable or unfavorable devolves upon assessment of whether Terri would have wanted to continue existing in a persistent vegetative state. This in turn hinges on medical prognosis. Although we acknowledge some difference of opinion regarding Terri’s
prognosis, by the preponderance of expert opinion, further treatment would have been futile, and she would have had no quality of life. By the quality of life criterion, therefore, it was ethically permissible to allow her to die.

**Contextual Features—Socio-Economic, Personal, and Institutional**

Vital medical decisions are never made in a social vacuum, but within the context of an individual’s upbringing, her family and friends, social and cultural institutions, the law, and economic influences. It is important to consider all contextual elements in reaching an important medical decision, as the decision can have a lasting effect on other persons and institutions, as well as on the patient.

Should a medical decision take into account the considerations of others? Yes, it should, and in particular it should account for close family members. However, here we come to the most wrenching aspect of the case: the conflict and antagonism between Terri’s parents and her husband. Terri’s parents said they desperately wanted to keep her alive, so stopping treatment and allowing her to die would have hurt them deeply. On the other hand, if Terri’s husband believed strongly that she should not be kept alive, a decision contrary to that wish would have hurt him. Can we say the parents’ emotional pain at seeing her die was greater than the husband’s pain would have been had she been kept alive? From reports in the public media, and from the lengths to which her parents went to keep Terri alive, we can say “perhaps so.” Did years of continued treatment after Terri’s husband first asked to have the tube removed cause him pain? Perhaps so. What matters is whether a decision one way or the other would cause undue emotional harm to either of the parties.

The perception, by outsiders like us looking at the case, of harm to either Terri’s parents or to her husband, is undoubtedly influenced by characteristics, beliefs and values, and economic or social gain or loss of the opposing personalities in the case. For example, the personal religious convictions of Terri’s parents may have played a large role in wanting to keep her alive. Also, the relationships of the loved ones to Terri, and observers’ ability to identify with either the parents or the husband, may influence outside observers’ views of right and wrong.
Our perception of emotional harm is also influenced by our own personal values and beliefs. Assessing harm to others intimately involved in the case also would involve value judgments based on information gleaned from the public media. It would be wrong, we believe, to judge the degree of harm to the parents or husband based on our opinion of the reasons or underpinnings of their wishes, or perceived personal characteristics of the disputants. Further, this concern for others is disproportionately small compared with what was best for Terri.

We must also consider the impact of our ethics decision on institutions and religious or cultural groups that may believe they will be impacted by the decision. In July 2004, based on a speech in which Pope John Paul II said it is obligatory for physicians to tube-feed patients in persistent vegetative states, Terri’s parents filed a motion aimed at stopping withdrawal of the feeding tube (see Cerminara’s article). This statement was contrary to what was then a near consensus in the medical ethics community in the United States—namely, it is ethically permissible to withdraw food and hydration in a patient in a persistent vegetative state if the patient or the patient’s surrogate so desires. This finding was also affirmed by the U.S. Supreme Court (Cruzan v. Director, Missouri Department of Health, 1990). Would a decision to stop treatment through a feeding tube cause harm to the Church? Many “right to life” advocates objected strenuously to removal of the feeding tube, often on ideological grounds. Would removing the feeding tube harm these groups and individuals?

These are contextual “macro-issues” of how individual medical decisions can influence or alter institutions and policies that affect large groups of people or entire populations. Although macro-issues introduce important considerations, we cannot give them great weight in this case. Unless there is a clear and overwhelming public consensus, there are usually multiple opposing forces concerning a contentious social issue. For example, although “right to life” individuals may feel harmed by a policy permitting cessation of feeding for a patient in a persistent vegetative state, “right to die” individuals may perceive harm from a converse policy. One of the primary goals of medical ethics is to protect the individual patient from public policies and institutions potentially harmful to the individual’s values or goals. The prime consideration must be the welfare and desires of the patient, not of social policy or institutions.
Another macro-issue is the allocation of scarce resources. Using a “utilitarian” approach, we would make medical decisions to create the most good for the most people. Thus, one might argue that the resources necessary to keep someone alive for 15 years in a persistent vegetative state would be better allocated to provide basic health care for others who have no health insurance or cannot get adequate health care. The expenditure of resources of this order and magnitude is not trivial. However, although individual cases may bring national attention to social inadequacies, broader societal issues such as allocation of scarce resources are better handled on a macro scale of policy-making. The preponderance of weight in individual medical ethical decisions must be directed to considerations of what is best for the individual patient.

If contextual factors (perceived harm to the relatives of one side or the other; religious beliefs; political, economic, and legal desires) were overwhelming, they might tilt our judgment. Such not being the case, however, the ethical decision must rest firmly on assessment of what was best for the patient. In the end, in Terri’s case all these contextual factors are minimal or are subsumed under the ethical considerations of beneficence and the patient’s preference.

Comment and Conclusions

By applying the classic elements of medical ethics, we find that it was ethically permissible and appropriate to stop Terri Schiavo’s treatment by use of a feeding tube. After 15 years with no sign of improvement, it is unreasonable to conclude that continued tube feeding would have led to clinical improvement. When the outcome is uncertain we should err on the side of maintaining life. But a helpful ethical maxim is that it is better to stop a treatment that was tried and did not work than to not start a treatment that has an uncertain outcome. This maxim was definitely followed in this case!

The ramifications of the case are numerous if not legion by now and deserve the attention of all Americans. We believe the case’s most important lesson is the need for advance directives. The immense hostility and divisiveness engendered, individually and nationally, may be even more likely to recur in a future case of a patient in similar circumstances. The case has caused an unnecessary social divide.
In future cases involving care of patients in persistent vegetative states, violent disagreements as in the Schiavo case may be avoided by a full and early application of the principles of medical ethics. Just as importantly, the public needs to be informed of this approach to ethically difficult medical decisions, and the media should make use of it in their reporting. In our opinion, the inordinate and sensationalist media attention to the Schiavo case, with the marked emotional reactions of so many individuals and groups, detracted greatly from an understanding of the ethical principles that should have been applied to a determination of what was best for Terri.

The medical ethics approach is not intended as an all-encompassing set of rules for clinical decision-making. In a rare public reference to bioethics, a syndicated columnist said the discipline had become a secular tool and blamed “left-leaning bioethics” for justifying the “killing” of people such as Terri Schiavo (Leo, 2005). We acknowledge the secular basis of medical ethics as necessary to establish guidelines for all physicians without imposing specific religious or spiritual beliefs on those who do not share them. How physicians and others superimpose their religious or spiritual beliefs on medical ethics is a matter of individual values and goals. One may supplement medical ethics with personal principled beliefs, but we urge all to understand that in medical ethics “one size does not fit all.” There must be room to apply the principles of medical ethics within diverse sub-cultures.

Part of the problem, we believe, has been a misplaced focus on “pulling the feeding tube,” rather than on the basic ethical question of the treatment Terri was receiving. By focusing only on the final act of withdrawing food and fluids, with its attendant symbolism to some of “killing,” one cannot understand the patient’s medical condition, the role of prior medical decisions, and the need for medical ethics in reaching a decision.

Fundamental to an understanding of dying patients is the nature of earlier decisions, particularly treatments. Any life-extending treatment decision is a choice to defer dying to a later date and, most likely, under different conditions. Continued provision of artificial nutrition and hydration to Terri would not have fulfilled the ethical goals of medical treatment—it could have only postponed, not prevented death.
Dying has been postponed by human choice when we artificially feed or breathe for a patient. The treatment is the key ethical issue, as without it the patient dies; however, with continuous treatment there is a continuous deferral of dying to a later date. The problem with continuing treatment after the prognosis is clear is exactly what happened to Terri. Once natural death is overcome medically, and there is no medical reason to expect recovery, someone must make the decision about how and when to allow death to proceed.

The issue is not “killing,” or depriving a disabled person of life, but when to stop an unsuccessful treatment in order to allow death that has been unnaturally postponed. Medically, it seems reasonable to continue treatment for up to a year after a patient is diagnosed as being in a persistent vegetative state, although many neurologists might argue it is futile to treat after six months, or even less. But after the long-term outlook is clear, the choice is whether to allow a patient to die, as would have been Terri’s choice based on the best evidence, or to wait and let her die years later, as her parents wished. Either way it is a human decision someone had to make.

Most Americans still die in institutions such as hospitals and nursing homes where decisions are made whether to resuscitate, to treat life-threatening complications, to try more curative therapy, or to withdraw life-sustaining treatments (Faber-Langendoen & Lanken, 2000; Field & Cassel, 1997). When patients are at the end of life and not capable of making medical decisions, loved ones often make decisions to stop treatments and let them die instead of extending “life” to the limits of modern technology. This is not killing, it is allowing death to proceed rather than extending the dying process. After life is first prolonged by medical management, it is allowed to end sometime later. It was the same for Terri Schiavo, and it is ethically correct.

References


