WHAT WOULD TERRI WANT?
ON THE PSYCHOLOGICAL CHALLENGES
OF SURROGATE DECISION MAKING

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The Terri Schiavo case was unique in the media attention it garnered, but the
decision making challenges faced by Terri’s family are common ones encountered
by all families who must make choices about the use of life-sustaining medical
treatment for an incapacitated loved one. This article highlights three key issues
that were particularly problematic in the Schiavo case, but that represent general
psychological challenges inherent to the task of surrogate decision making. The 3
central points of uncertainty, and therefore conflict, in the Schiavo case concerned:
(a) the appropriate standard by which medical decisions for Terri should be
made, (b) the specific nature of Terri’s wishes about the use of life-sustaining
medical technology, and (c) the true extent of disability and prognosis for recovery
represented by Terri’s medical condition. No simple remedy is possible that will
resolve all of the uncertainties inherent to surrogate decision making, but some
general strategies for improving the quality of end-of-life medical decisions are
discussed.

The tragic final chapter of Terri Schiavo’s life story was unique in
many ways. Even in an era saturated with celebrity trials and
confessional television talk shows, seldom has such an exquisitely
personal decision been elevated to the level of full-blown, 21st-
century style public spectacle. Discussions normally held in rever-
ent tones within the dimly lit corridors of hospitals and hospices
were magnified by a 24-hour news cycle and an ongoing culture
war into a national conversation. The situation seemed uniquely
cursed with every difficulty that might befall a family striving to
make the right decisions for an incapacitated loved one. Irreconcil-
able differences between family members about the appropriate
course of action, the lack of any written documentation of Terri’s

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wishes about the use of life-sustaining technology, and ambiguity about her level of disability and prognosis for recovery, all created a confluence of uncertainty that seemed only to fuel the moral outrage among active partisans and make simple, comfortable resolutions difficult for almost any thoughtful observer.

In many other ways, however, the issues faced by Terri Schiavo’s family were not at all unusual. Every day thousands of families in the United States and around the world must make decisions about whether to prolong a loved one’s life “artificially” with medical treatment.1 Every day families disagree about how such decisions should be made, are uncertain about what their loved one would have really wanted, and wrestle with doubts about giving up the fight for their loved one’s life too early or too late. The end of Terri Schiavo’s life was unique largely in the number of different factors that conspired to complicate decision making on her behalf, and consequently, in the intensity of the media attention that this particularly thorny case received. Taken individually, however, the challenges faced by the Schiavo and Schindler families are all too common ones, and thus an analysis of them can help generate insights that are applicable to the challenges inherent in end-of-life medical decision making more generally.

In this brief article, I will examine the Terri Schiavo case through the lens of psychological research on end-of-life medical decision making. I will identify three points of uncertainty and disagreement that were brought into sharp relief in the Schiavo case, but that represent general categories of problems faced in almost all instances when decisions about the use of life-sustaining treatment must be made for incapacitated individuals. I will conclude with a discussion of some lessons we might learn from the Schiavo case about how to better approach such decisions in the future, but with this disclaimer: there is no easy fix that will make end-of-life decision making simple and conflict-free. The line between life and death will always be blurry, and there will never be a sure way of knowing the wishes of an individual left wishless by the ravages of injury or disease. Despite many commentators’ quick leap to

1It must be noted that decisions about the use of life-sustaining medical technology are really only a relevant concern in the developed world. In the majority of countries around the globe, concerns about stopping medical treatment for individuals who no longer believe their life is worth living are overwhelmed by concerns about providing medical treatment for individuals whose lives are still clearly worth living.
endorse living wills as the sure path to avoiding Terri and her family’s sad fate, resolving the uncertainty and conflict inherent in end-of-life medical decisions will never be as easy as just filling out a form.

**Self-Determination, Surrogate Decision Making, and Substituted Judgment**

The fundamental right of individuals to control the important decisions in their lives, especially regarding their own health and bodily integrity, is well founded in United States law and embodied by the traditional American values of personal liberty and privacy. These rights are generally acknowledged as giving a competent patient the freedom to refuse any form of medical treatment, even if that treatment is necessary to sustain his or her life. Ethical analysis and legal decision are equally well agreed that this fundamental right to self-determination is not diminished when a formally competent individual becomes decisionally incapacitated because of illness or injury (Cruzan v. Director, Missouri Department of Health, 1990). And herein lies the challenge: How can an individual who is currently incompetent, as Terri Schiavo was during the last 15 years of her life, exert her right to make decisions for herself?

This is only possible if others make decisions for her, but do so in a way that faithfully represents the decisions she would have made for herself if able. This process, referred to as substituted judgment (Baergan, 1995; President’s Commission, 1983), is consensually accepted as the most desirable method of making decisions for incapacitated patients precisely because of the ethical priority accorded to self-determination in medical decision making (Buchanan & Brock, 1990; President’s Commission, 1983). That is, rather than representing a surrogate decision maker’s beliefs about what is best for the patient, the substituted judgment standard requires surrogates to remove their own wishes from the decision making process, and strive only to represent the patient’s preferences regarding the use of life-sustaining medical treatment.

From a legal and ethical standpoint then, it is clear that the decision about whether to terminate the provision of nutrition and hydration to Terri Schiavo was Terri’s decision to make. Because Terri was no longer able to make that decision for herself,
however, the task facing her loved ones was to ask themselves the essential substituted judgment question, “What would Terri want?”

It will be my contention in the following sections that honoring the wishes of an incapacitated individual is no simple psychological feat. Not only must the surrogate remain focused on the task of predicting the patient’s wishes in the face of other competing standards that might be used to make decisions on the patient’s behalf, but prior indications of the patient’s wishes, even formal ones recorded in advance directive documents, are seldom as helpful as most people imagine when it comes to predicting how the patient would make a specific decision about the use of a particular medical therapy in a particular set of clinical conditions. An analysis of the conflict in the Schiavo case can be generally instructive in that its very intensity serves to highlight issues that are actually quite common, but normally struggled with in less dramatic fashion.

The three central points of uncertainty, and therefore conflict, in the Schiavo case concerned: (a) the appropriate standard by which to make decisions on Terri’s behalf, (b) the specific nature of Terri’s wishes about the use of life-sustaining treatment, and (c) the true nature of Terri’s level of disability and prognosis for recovery. These points will be discussed in turn, first in terms of how each played out in the Schiavo case specifically, and second with an emphasis on identifying issues of general concern in end-of-life medical decision making.

Conflicting Values

Based on the precedent set by *Cruzan v. Director, Missouri Department of Health* (1990) and supported by Florida State Law, the legal decision regarding the removal of Terri Schiavo from artificial nutrition and hydration hinged on the provision of “clear and convincing” evidence that this act was consistent with Terri’s wishes. As such, the legal arguments presented by the two sides were primarily framed in terms of honoring Terri’s wishes, and therefore, her right to self-determination. In fact, the ability of Terri’s husband Michael to so consistently prevail in the numerous judicial proceedings (see Cerminara’s article) was likely due to the discipline shown by his legal team in terms of characterizing their case solely as an issue of carrying out Terri’s own desire to be removed from artificial life-support.
The arguments presented by the Schindler family’s legal team, and those presented in the media by the Schindlers’ and their various supporters, were much less disciplined. At times the argument was made that Terri would not have wanted her feeding tube removed. This was asserted variously on the basis of either statements she supposedly had made as an adolescent watching television reports about the Karen Ann Quinlan case or on her Catholic faith.

At other times, however, the argument for maintaining Terri’s nutrition and hydration revealed an ethical stance directly opposed to arguments based on her right to self-determination. For example, in a detailed report on the case written for Florida Governor Jeb Bush after the passage of “Terri’s Law” by Florida State Legislators, the court-appointed Guardian Ad Litem reported that the Schindler family members explicitly stated during court testimony that “even if Theresa had told them of her intention to have artificial nutrition withdrawn, they would not do it” (Wolfson, 2003, p. 14). The sentiments of the Schindler family are of course understandable, and best attributed to a purely emotional desire to keep their loved one alive rather than any explicit consideration of abstract ethical principles. Other participants in the legal and media debates, however, made statements more explicitly based on a “right to life,” suggesting that Terri should continue to receive nutrition and hydration, not because she would have wanted to, but because of an ethical obligation to maintain life if the means to do so are within reach. A softer version of this argument was revealed in repeated assertions by President George W. Bush and others that end-of-life medical decisions should “err on the side of life.”

At least three other distinct ethical arguments can be identified that were made in support of maintaining Terri’s treatment. Closely related to the right-to-life argument, disability rights advocates argued that Terri’s nutrition and hydration should be maintained because its discontinuation would reflect a devaluation of the lives of the cognitively disabled. Another argument heard frequently in the media coverage was one based on parental rights; that Terri’s mother and father had a fundamental right to maintain her life if they so desired (e.g., “If her parents are willing to take care of her, why not let them?”). Finally, a number of statements made about the case revealed an implicit reliance on the “best
interest standard” that is generally considered an important principle in surrogate decision making, but only if the substituted judgment standard cannot be applied (Buchanan & Brock, 1990). Examples of this range from the oft-cited concern that removal of artificial nutrition and hydration would cause Terri pain and suffering, to the assertion made by Schindler attorney David Gibbs in his argument to Federal Judge James Whittemore (and recounted in the motion later submitted to the U.S. Supreme Court) that because of its conflict with Terri’s Roman Catholic faith, terminating her nutrition and hydration could “jeopardize her eternal soul.”

The sheer volume of commentary on the Schiavo case insured that a wide range of different perspectives would be applied to understand and argue it. But the more general point should not be missed. In any case where family members must make medical decisions for an incapacitated loved one, there is bound to be anguish, uncertainty, and quite often conflict regarding the appropriate standard by which decisions should be made. Potential value conflicts may often be difficult to resolve because people seldom hold explicit ethical positions that they can readily articulate. Rather, individuals tend to respond to ethical dilemmas based on intuitive, emotion-based moral rules (Haidt, 2001), and thus it may be hard for family members to identify the sources of their disagreement and address them. Finally, although the right to self-determination holds a pre-eminent place in United States case law guiding end-of-life decision making, this value hierarchy is hardly universal. Not only do individuals differ in their personal desire to control their own end-of-life medical care (Hawkins, Ditto, Danks, & Smucker, 2005), but cultural and religious differences clearly exist in the value ascribed to patient autonomy relative to other decision making standards such as the right-to-life or family-based decision making (e.g., Blackhall, Murphy, Frank, Michel, & Azen, 1995).

As such, the conflict seen in the Schiavo case regarding the appropriate values by which to guide decisions about Terri’s care, although unusually intense, was hardly unusual. It would seem the exceptional case when family members experience no emotional ambivalence nor value conflicts when faced with a decision about whether to discontinue life-prolonging medical treatment for an incapacitated loved one.
Conflicting Views of Terri’s Wishes

A common refrain in the media coverage of the Schiavo case was that the entire conflict would have been avoided if only Terri had expressed her wishes in a living will or some other form of advance directive prior to her collapse. This assertion is challenged of course by the analysis just presented suggesting that the various factions differed sharply regarding the weight that should be accorded to Terri’s wishes even if she had made them known. Still, to the great majority of individuals concerned with Terri’s fate, the most problematic aspect of the case was the uncertainty surrounding what Terri would have wanted if only she could have spoken for herself.

This point is crucial because, ironically, it was the court’s conclusions about the nature of Terri’s wishes that played a central role in the ultimate decision that her nutrition and hydration could be terminated. Testimony by Michael Schiavo and two members of his family indicated that Terri had expressed her desire to be removed from artificial nutrition and hydration based on statements she had made indicating a general desire not to become a “burden” and not to have her life prolonged artificially with “machines” and “tubes.” These statements were vague, and their veracity was questioned by the Schindler family, but ultimately the court accepted this testimony as clear and convincing evidence of Terri’s wishes.\(^2\) It was thus upon the power of these general verbal statements that the courts upheld Michael Schiavo’s authority to honor Terri’s wishes and remove her from the machines and tubes that were maintaining her life.

Among people who approached the Schiavo case without deep valued-based convictions, it was likely the fact that such a momentous decision was based on such less than definitive evidence that was the source of their greatest discomfort. Once again, however, this kind of uncertainty is more likely the rule than the exception. First, like Terri, most people die without an advance directive. Despite years of enthusiastic advocacy by major health care organizations and the widespread passage of state and federal

\(^2\)Statements offered by the Schindler family suggesting that Terri would not have wanted to be removed from life-support were deemed less credible by the court because they occurred when Terri was a child and referred only to Terri’s feelings about Karen Ann Quinlan rather than specifically to Terri’s wishes for her own medical treatment.
law encouraging their use, fewer than 25% of Americans are estimated to have any kind of advance directive (Eiser & Weiss, 2001). Completion rates are even lower for many ethnic groups (Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998) and even seriously ill individuals have been found to complete living wills at rates only slightly higher than those found in non-patient populations (Holley, Stackiewicz, Dacko, & Rault, 1997; Kish, Martin, & Price, 2000).

Second, even when individuals complete advance directives, these directives seldom provide clear instructions that can be used to guide actual medical decisions. One study, for example, found that only 5% of directives completed by a sample of seriously ill patients contained any specific instructions about the use of life-sustaining treatment (Teno et al., 1997). The majority of the directives were either durable powers of attorney (simply naming the individual they wanted to make decisions for them) or contained only vague instructions with unclear implications for the patient’s actual medical condition (e.g., “no heroic measures”).

Finally, even when individuals complete directives containing relatively specific treatment instructions, these directives may still do little to improve surrogates’ understanding of the patients’ treatment wishes. First, no directive, no matter how detailed, can cover all medical eventualities (Brett, 1991). Even specific directives will often require surrogates to infer patients’ current preferences from those stated for similar but not identical treatments or conditions. Second, surrogate decision makers show persistent biases in their predictions of their loved one’s treatment wishes (Fagerlin, Ditto, Danks, Houts, & Smucker, 2001). Together these factors may account for the results of a study that found that allowing a surrogate to review a detailed advance directive completed by a loved one did not improve the surrogate’s ability to predict that loved one’s life-sustaining treatment preferences (Ditto et al., 2001).

One bias that has been documented in surrogate substituted judgment is a projection bias (Fagerlin et al., 2001; Schneiderman, Kaplan, Pearlman, & Teetzel, 1993). That is, when trying to predict another person’s desire for life-sustaining medical treatment, surrogates often err by assuming that that individual will have wishes similar to their own. Although not inherently irrational (many people likely approached the Schiavo case by imagining what they would want if they were in Terri’s condition), projection is a common source of misprediction. It is not hard to imagine that Terri Schiavo’s family might have been influenced by this tendency to believe that Terri’s wishes were likely to be similar to their own.
Conflicting Views of Terri’s Medical Condition

So far, I have argued that family members often bring differing moral standards to bear on difficult decisions about how to treat an incapacitated loved one and there is often uncertainty and disagreement regarding just what that loved one would want if he or she could only say. The Schiavo case, however, was plagued with one additional source of uncertainty that might seem less typical than these others: the uncertainty that surrounded the actual nature of her medical condition.

Although space considerations preclude a full description of the intricacy of the two factions’ beliefs about Terri’s actual medical history, the opposing positions boil down to this. According to Michael Schiavo, his wife Terri was in a persistent vegetative state, with no chance of improvement or recovery and was responsive to environmental stimulation only at a rudimentary, reflex level. According to Terri’s parents and siblings, Terri was in a condition that is generally referred to as a “minimally conscious state,” with the potential for some substantial degree of recovery if aggressive treatment was applied, and was aware of and emotionally responsive to their presence (and perhaps even capable of expressing her wishes and intentions).

The dramatically different portrayals of Terri’s medical condition added another level of decision making complexity onto an already challenging situation. If one accepted Michael’s assessment of Terri’s medical condition, two things reasonably followed: (a) there was little of “Terri” left to save even if saving her was possible, and thus terminating the treatment that prolonged her marginal existence was morally justifiable; and (b) Terri likely would not have wanted to have her life prolonged if she had no significant cognitive function and no chance of ever recovering it. Conversely, if one accepted the Schindler’s assessment of Terri’s condition, two quite different things could be reasonably concluded: (a) it was morally wrong to deny treatment to a person with some ability to think and reason and a substantial likelihood of recovery, and (b) Terri would likely have wanted her nutrition and hydration continued if she knew that she might be able to recover and regain some reasonable quality of life. Thus, true knowledge of Terri’s actual medical condition had dramatic implications for what could be perceived as the “right” decision to make.
on her behalf, both in terms of the direct moral implications of the act of withdrawing treatment, and in what the nature of her condition would imply about honoring Terri’s own treatment wishes.

Unfortunately, uncertainty about patients’ prognoses for recovery often accompanies, and complicates, end-of-life medical decision making. Perhaps the single piece of information that people find most helpful in making end-of-life decisions is a clear sense of whether the patient is likely to regain an acceptable quality of life. Hypothetical statements about end-of-life wishes are often stated confidently because they assume an unambiguous prognosis (e.g., “I would definitely not want to be kept alive if there was no chance that I would recover”). Prognostic certainty, however, is a rare commodity. Medical prognoses, by their very nature, are statements of probability. Moreover, the uncertainties involved in real clinical situations are often complex and multiple, involving more than just a single probability of full recovery given one particular treatment approach.

As was well illustrated by the Schiavo case, uncertainty about a loved one’s prognosis for recovery creates uncertainty about the appropriate course of action. The problems caused by this uncertainty are often compounded by the fact that family members may have a powerful emotional desire to maintain the belief that their loved one will recover. Psychological research provides clear evidence that such motivations can bias assessments of the likelihood of unwanted outcomes (Weinstein, 1980) and thus make family members reluctant to end their loved one’s treatment even when the medical probabilities are reasonably clear. It might be argued that one of the primary sources of the intense conflict seen in the Schiavo case was the (understandable) difficulty Terri’s parents and siblings seemed to have had accepting the prevailing medical opinion (confirmed by a subsequent autopsy report) that Terri’s brain damage left her with no significant cognitive function and no reasonable chance for recovery.

The Legacy of the Schiavo Case

The public attention generated by the final weeks of Terri Schiavo’s life will almost certainly spawn well-intentioned legislative efforts to address the difficult issues that surround end-of-life medical decision making. It is crucial, however, that these efforts be more
than just well-intentioned. Lawmakers must approach the problem with a full appreciation of the complexity of the challenges involved, and in this final section, I suggest what form attempts to address them should and should not take.

Clearly the most problematic form legislation could take would be to attempt to require in some way that under conditions of uncertainty, surrogate medical decisions err on the side of life. Although such a provision might seem reasonable at first blush, it is important to recognize that the impetus for the advance directive movement was widespread public concern about the aggressive use of advanced medical technology to prolong the dying process. Given the ubiquity of uncertainty in end-of-life situations, a requirement to err on the side of life would institutionalize this fear of pointless medical treatment and repudiate 15 years of state and federal legislation designed to address this very problem.4

The other less ominous, but potentially equally misguided reaction that policymakers might have to the Schiavo case is to continue to push people to complete more and more specific instructional advance directives. From a strict self-determination perspective the push toward greater specificity makes perfect sense; however, it is unlikely that even a specific instructional directive will provide the clarity surrogates seek regarding the wishes of an incapacitated loved one (Ditto et al., 2001). Consider this example: Suppose Terri Schiavo had documented this statement in her living will: “I do not want life-prolonging medical treatment if I am in a persistent vegetative state with no chance of recovery.” Would this statement, which is more specific than the kind of statements found in most living wills, have resolved the uncertainty and conflict surrounding this case? By “life-prolonging medical treatment” did Terri mean artificial feeding and fluids? Some people would, others would not. Was Terri in a persistent vegetative state? Her husband says she was, but her parents and siblings disagreed. Did she have a chance of recovery? How big a chance? How big a chance is big enough that we could all agree that Terri would have wanted to take the risk?

4It is also important to note that such a requirement would almost certainly undermine self-determination in many instances. For example, both public opinion polls and some published research (e.g., Ditto et al., 2001) suggest that a clear majority of the American people would have wanted treatment terminated if they were in a medical situation similar to Terri Schiavo’s.
Even if one argued that these ambiguities could be addressed with ever greater specification of wishes, there are two other important problems with the push toward specificity in advance directives. Numerous studies have shown that preferences for specific life-sustaining medical treatments show substantial instability over time and can be affected by changes in the respondent's physical and emotional condition or even the way the questions are asked (e.g., Ditto et al., 2003; Forrow, Taylor, & Arnold, 1992). Thus, even if people could be encouraged to document highly detailed treatment preferences, it is not at all clear that these preferences would be meaningful. Second, and perhaps more importantly, research suggests that the majority of people have little desire to exert tight control over the decisions made for them at the end of life. Many patients state that they are quite satisfied leaving end-of-life medical decisions to their families (Holley et al., 1997) and feel comfortable letting surrogates override their living wills if the surrogate thinks it in their best interest (Hawkins et al., 2005; Sehgal et al., 1992).

What this suggests is that a more psychologically feasible goal, and one more consistent with the degree of control most individuals actually desire over end-of-life medical decisions, would be to encourage general advance directives and thus a more general form of self-determination. A commitment to self-determination requires not that people be forced to make decisions that they feel ill-equipped to make, but only that people be provided the level of control they desire. An important step in this regard would be to refocus attention away from instructional advance directives and toward encouraging the completion of proxy advance directives, such as durable powers of attorney for health care. What people seem to want most is to have someone they trust make medical decisions for them, in most cases with some general guidance about the values and goals that they want to steer these decisions. Viewing living wills as a way to communicate general wishes rather than as an end in themselves captures the way most individuals want their living wills to be used (Hawkins et al., 2005). Moreover, it suggests the importance of embedding the completion of advance directives in a more extensive process of advance care planning. Clearly the most useful role for instructional advance directives, including specific ones, is as a stimulus for ongoing discussion among one’s family members and health
care providers. Viewing living wills as the beginning of a communication process rather than its end product, and surrogate decision making as guided by patients’ desire to inform rather than dictate medical decisions, will lead to an end-of-life decision making process that is most likely to satisfy the needs and goals of both patients and the loved ones struggling to make decisions on their behalf.

Cases like those of Terri Schiavo, Nancy Cruzan, and Karen Ann Quinlan make up only a tiny percentage of all instances where decisions about the use of life-sustaining medical treatment must be made, but attract disproportionate attention precisely because they evoke particularly profound and difficult moral and practical questions. Such cases will always exist. Although no approach to improving end-of-life decisions will ever make it easy, with a concerted and collaborative effort on the part of politicians, health professionals, and researchers, policy and law can be developed that can help many families negotiate the difficult and inevitable challenges of making decisions for an incapacitated loved one. Although we can never know for sure, I suspect that this would be an outcome that Terri Schiavo would have wanted.

References


