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Terri Schiavo and End-of-Life Decisions: Can Law Help Us Out?

The case of Terri Schiavo was the most litigated medical case in history. It was the focus of legislatures and courts at both the state and federal levels. Indeed, it spawned its own "private" law, passed by the Congress in an effort to give the federal courts special jurisdiction to hear it. For all that, though, can we say that Terri Schiavo was well-served by the law? By the time she died, tens of thousands of words had been written about her life and death by attorneys, judges, journalists, advocates, pundits, health care professionals, ethicists, and ordinary folks. Much of it focused on determining, or arguing, "what Terri would have wanted" in terms of end-of-life care. I believe it is safe to say that whatever Terri's choices would have been regarding the provision or withholding of artificial nutrition and hydration, she would not have wanted what actually happened. Would she, or anyone, ever choose to be survived by a family at war with itself?

It has been reported generally that for the 5 years following the heart attack that left Terri in a persistent vegetative state, her husband and parents cooperated in her care. What happened? Terri's story is a cautionary tale about the ways in which loving and well-intentioned family members who believe that they are acting in behalf of a loved one (for no one ever seriously asserted that either Terri's husband, Michael Schiavo, or her parents, the Schindlers, were motivated by anything but concern and love for Terri) can lose their way in a legal system in which litigants necessarily become combatants. What lessons can we draw from the tragedies of this story to help us avoid leaving a similar legacy of controversy and anger?

The law is a valuable and powerful instrument when put to purposes for which it is intended. It is an essential tool for restraining an overreaching government. It offers us the security of knowing that those who would do us harm may not do so with impunity. It assures societal order and predictability. However, as with any tool, when used in ways for which it was not designed, the law can cause great harm. When introduced into intimate personal relationships, whether between family members or friends or between doctor and patient, it can have devastating effects.

From Personal "Story" to Legal "Case"

What happens to a very human drama, such as the one that played out in the Pinellas County, Florida, nursing home and hospice where Terri Schiavo received care, when it is subjected to judicial process? Litigation by its nature imposes a particular frame upon what may be, and in this case certainly was, an almost unimaginably emotionally complex story. It forces that story into a form that cannot fully capture and often distorts the story itself. Most significantly, when the individuals who are the participants in such a story are converted into parties in a lawsuit, they necessarily fall on one side or the other of the line dividing "plaintiff" from "defendant." Their positions become oppositional; their understanding of their respective interests no longer can accommodate the ways in which such interests previously coincided, overlapped, or were interwoven. Within the adversarial framework of litigation, winning is all, and winning means that one party's set of rights and interests prevails over those of the other.

No matter how the various parties previously perceived the relationships and interests they had at stake in Terri's unfolding life story, once that life became the subject of litigation their relationships and interests became redefined in light of the competition of opposing rights. The contest of opposing rights and/or interests is the only paradigm to which our adversarial legal system is adapted. The question giving rise to the legal battles in the Schiavo case therefore was, in essence, "To whom, between Terri's husband and her parents, did the right to make end-of-life decisions for Terri belong?"

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Whereas most rights conflicts are conflicts between the rights held by two or more different individuals, the essential rights in conflict in the Schiavo case were both held by the same person. At stake were Terri's constitutional, statutory, and common law right not to be deprived of life and her constitutional, statutory, and common law right to bodily integrity, as the United States Supreme Court said in its opinion in the Cruzan case, "to the possession and control of [her] own person, free from all...interference of others..." Although her husband and parents came to embody these competing rights, the rights at stake both belonged ultimately to Terri.

Unlike litigation in which conflicting rights are asserted by two or more individuals, what constitutes "winning" and what constitutes "losing" a lawsuit becomes unclear at best where, as here, the rights fundamentally at issue are held by a single person. In Terri's case, one of her rights would have to yield to the other. Regardless of which of Terri's rights prevailed, she would lose the other. The medically provided nutrition and hydration that Terri was receiving were life sustaining. Terri could not continue both to be alive and be free from invasive medical procedures. Can there be a more momentous choice to be made? Terri was, of course, unable to make this choice for herself, and yet the choice had to be made.

Deciding for Those Who Can't Decide

A consensus has developed that originated with bioethicists but now includes the courts, the medical community, and society generally: when a patient is no longer able to make medical treatment decisions for herself, care providers and those who know the patient well should try to effectuate the treatment choices she would have made. This is the *substituted judgment standard* of surrogate decision-making. Substituted judgment is regarded with approval as a way of carrying the value of patient self-determination forward into a time when the patient is incapable of autonomy. Prior to the development of the notion of substituted judgment, medical decisions for the incapacitated were made on the basis of others' (doctors and/or family members) assessment of what would be in the best interest of the patient. This is now referred to as the *best interests standard* for medical decision-making, and is relied upon when there is no information about what the patient might have wanted.

However much we might welcome the standard of substituted judgment as an extension of patient autonomy, we also must be aware of the potential for the radically different understandings of the patient and his or her wishes that give rise to the sort of conflict that arose between Michael Schiavo and the Schindlers. When surrogate decision-makers and care providers cannot agree upon what that choice would have been, they may turn to the courts to determine either what the now-incapacitated patient would have chosen or who is best situated to choose as the patient would have.

The judges' charge is to base their determination on the evidence before them. Our legal system is grounded in the belief that cases should be decided on the basis of established legal principles and the evidence presented, not on the basis of the personal philosophies, predispositions, religious beliefs, or moral commitments of the individuals who sit in judgment. It is helpful to keep in mind that for every time the law and the evidence lead a judge, perhaps in spite of even his own sympathies, to a decision we deplore, there is another time when the law and the evidence compel a judge, in spite of her own sympathies, to render a decision we applaud.

Are Advance Directives the Answer?

Overall, this is a most effective and fair system. However, as noted earlier, the very process of litigation imposes changes on the story that is at its center. It may, for the sake of making an effective argument, reduce a richly complex narrative into a simple plot line; individuals may be drawn in ways that make them unrecognizable to themselves and to others. As the Schiavo case dragged on, it became clear that replacing decision-making based upon others' assessment of what is in one's best interests with a standard of substituted judgment is not enough to ensure that the end of life would be as one would choose.

The problem, it seemed, was that Terri had not *legally* named the person she wanted to make decisions for her. Bioethicists, attorneys, medical care providers, and others have pointed to the case as a cautionary tale about the consequences of failing to execute an advance directive. Behind this warning is the belief that an advance directive will make inferences about what the patient would have wanted unnecessary because it will bring the voice of the patient himself or herself to the decision-making process. In this way, or so the thinking goes, the kind of disagreement and strife seen in the Schiavo case may be avoided.

The standard view on advance directives is that they uphold and extend self-determination, a fundamental American legal and political value as well as a premier value in Western medical practice (Wreen, 2004). But advance directives, while useful, are not panaceas. First, as statutorily created instruments, they only apply to situations to which the legislation creating them says they apply. In virtually every state, an advance directive to withhold or withdraw life-sustaining treatment becomes operative only when the patient is decisionally incapacitated and terminally ill or in a persistent vegetative state. Thus, they do not confer authority to withhold or withdraw treatment in a variety of situations that may call for decisions on just such issues. For example, one of the issues raised by the Schiavo case was whether Terri was actually in a persistent vegetative state or was in a state of "minimal consciousness." Assuming such a diagnosis becomes generally recognized as being distinct from the persistent vegetative state, under state laws as currently written, an advance directive might well be inoperative in such a case. Advance directives also are not effective to assure that a patient's choices, particularly regarding the withholding or withdrawal of treatment, will be honored until the very final stages of progressive illnesses such as ALS or dementia. This may be long after the patient would want her or his decision about care implemented.

Advance directives come in two forms: the living will and the appointment of a surrogate decision-maker. Living wills, or specific statements regarding which sorts of life-sustaining treatment one chooses to receive or to not receive at end-of-life, suffer the disadvantage of over-specificity; that is, they make explicit decisions regarding what are, at the time the choices are being made, hypothetical circumstances. The circumstances under which the actual decision must be made are rarely as clear-cut as the imagined situation. Complicating details not envisioned are almost invariably present (Wreen, 2004). Alternatively, the maker of a living will simply may have failed to consider a particular scenario. Yet, once a choice has been expressed in a living will, the law may require that the choice be effectuated even if it would appear that it is contrary to the decision the patient would make currently if he or she were able. As bioethicist Thomas Mappes has written, "Surely we do not show respect for patient autonomy by slavishly following a written instruction when there is compelling reason to believe that written instruction does not convey what the patient really meant to say [about the present situation]" (Wreen, 2004, p. 320).

The second form of advance directive, the appointment of a surrogate decision-maker, suffers from just the opposite infirmity; that is, the maker of the advance directive may name a person to make decisions for him or her without giving any specific information or instructions that would guide the surrogate in making such decisions. In a study of 45 surrogate decisions regarding CPR, which included both decisions to have resuscitation provided and to have it withheld, only in one instance did the relative say that she had previously discussed CPR with the patient (Sayers, Beckett, Waters, & Turner, 2004). Twenty-three relatives had no idea what the patient would have chosen and seven, although stating that they had never discussed the matter, claimed without supporting evidence to know what their relative would want. Some presumed to infer what the patient would have wanted, while some decided according to their own projected values. Authors found that while few of the relatives actually knew what the patients would have wanted for themselves because the topic had not been discussed, most reflected deep concern for the welfare of the patient. They concluded that these results demonstrate the difficulty in obtaining true substituted judgment.

Even when the surrogate decision-maker is relying upon the patient's prior statements to make a substituted judgment, all such statements may not be entitled to be given equal weight as evidence of what the patient's decision would be. As the New Jersey Supreme Court noted in *In re: Matter of Jobes*, the value of prior statements as evidence of the kinds of end-of-life treatments an incapacitated patient actually would choose to receive or forgo depends upon (a) how specific the statements were, (b) the amount of time that has elapsed between the time when the statements were made and when the decision needs to be made, (c) the consistency of the statements with each other and over time, and (d) whether the statements were thoughtfully made or were emotional and/or spontaneous exclamations. While naming a proxy decision-maker in an advance directive may help avoid the trauma of court battles, it may not, by itself, get us any closer to the goal of extending patient autonomy into the time when the patient is no longer capable of exercising self- determination on her own behalf.

Keep Talking

As these issues suggest, judicial and legislative involvement in end-of-life decision-making has not had the effect of ensuring that our personal visions of a good death will be realized. Yet, perhaps the ordeal of Terri Schiavo may provide us with a way to that end. Kielstein and Sass (1993) cited the benefits of using stories for developing advance directives. These advantages include the opportunity for spontaneous and direct personal response; a recognition of the ambiguities involved in moral choices; a recognition of the interrelatedness of facts, such as an illness and its treatment options, and the values that govern the choice of treatment; and a recognition of risks and uncertainties in diagnosis, prognosis, and intervention. In their work advocating the use of stories in the creation of advance directives, they developed narratives to be used to explore values and integrate them into the surrogate decision-making through advance directives.

The Schiavo case, in all its notoriety, can serve a similar purpose. We can use it to introduce difficult conversations about end-of-life decision-making with our friends and family. It offers a context within which we may consider what our own choices would be with awareness of all of the complexities and ambiguities that real life situations may present. It provides a starting point for sharing our values and choices with whomever we might want to have make decisions for us when we no longer can. It may do for us what the legal system could not do for Terri Schiavo — be the basis for honoring our personal ideas of a "good death." May this be a legacy of which Terri Schiavo would be proud. ■

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