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# Can we know what Terri Schiavo would have wanted?

JUDITH SCHWARZ, R.N., PH.D.,[1] AND NESSA COYLE, PH.D., FAAN[2]

[1]Compassion and Choices of New York, New York, New York
[2]Department of Neurology, Pain and Palliative Care Service, Memorial Sloan-Kettering Cancer Center, New York, New York

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## ABSTRACT

What would Terri Schiavo have wanted? That remains an unanswered question for many who followed the media frenzy that attended the extraordinary court and legislative battles that preceded her death 13 days after her feeding tube was removed for the last time. What would she have directed her physicians to do if she had "miraculously" regained capacity and awareness of the consequences of her cardiac arrest that left her in a persistent vegetative state? Who would she have wanted to make that decision for her if she were unable to do so? How are we to understand the meaning of statements that she purportedly made about life-sustaining treatments approximately 20 years ago, and how can we apply them to the current situation? This article reflects on those questions from the perspective of two small exploratory studies. These studies considered the meanings and interpretation of statements by terminally ill patients concerning desire for hastened death and the relevance of previously made statements to their current clinical situation.

**KEYWORDS:** Oral advance directives, Best interests, Who should decide, Terminally ill, Meaning behind the words, Desire for hastened death

Terri Schiavo was 20 years of age when she married Michael Schiavo in 1984. In 1986 the couple moved from Pennsylvania to Florida, where Terri's parents, the Schindlers, now lived. During the night of February 25, 1990, when she was 26 years old, she suffered a cardiac arrest and sustained hypoxic brain damage. Although able to breath on her own, she was unable to swallow, and a percutaneous endoscopic tube (PEG) was inserted soon after her injury. Some years later, she was medically determined to be in a persistent vegetative state (PVS) with virtually no hope for cognitive recovery.

Ms. Schiavo had not previously completed a written medical directive, nor had she appointed a surrogate or health care agent to make treatment decisions for her in the event that she lost decision-making capacity. In this regard she is like most Americans, and particularly like most young Americans, in not completing an advance medical directive. Her case was sadly similar to the two previously adjudicated "right to die" cases of Karen Ann Quinlan in 1976 and Nancy Cruzan in 1990—all three were young, white, middle-class women who suffered accidents that left them in a PVS and dependent on administration of artificial nutrition and hydration to sustain life.

What would Terri Schiavo have wanted? That remains an essential question for many who followed reports of her death 13 days after her tube feedings were stopped. What would she have directed her physicians to do if she had regained capacity and awareness of the catastrophic consequences of her cardiac arrest and subsequent hypoxic brain damage? (She was 27 years old at that time and had been married for 6 years.) Terri's parents, the Schindlers, and her husband, Michael, were unable to agree on the answer to that question. However, each was clear about

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Corresponding author: Judith Schwarz, R.N., Ph.D., Compassion and Choices of New York, 450 West End Avenue, New York, NY, 10023, USA. E-mail: judithschwarz@earthlink.net

what they wanted for Terri—Mr. and Mrs. Schindler wanted their daughter to live; they wanted her to continue receiving the life-sustaining nutrition and hydration provided via a surgically implanted PEG. Her husband wanted the tube feedings stopped and the PEG removed so that his wife could be allowed to die.

In 1998, Michael, her legally appointed guardian, petitioned the court to authorize the removal of Ms. Schiavo's PEG tube; the Schindlers opposed, saying that she would want to remain alive. Florida Circuit Court Judge Greer heard testimony from each side that included statements reportedly made by Terri Schiavo to five people, including her mother and husband. The judge's task was to determine whether or not there was clear and convincing evidence that Terri made "reliable oral declarations which would support what her surrogate (Petitioner/Guardian Michael Schiavo) now wishes to do" (Circuit Court for Pinellas County, FL, Probate Division, 2000). The judge used examples of statements purportedly made by Terri at different times to her husband and to his family as evidence to support his ruling in this case. They included statements to Michael Schiavo "prompted by her grandmother being in Intensive Care—that—if she was ever a burden she would not want to live like that," and another statement apparently prompted by her watching something on television regarding people on life support, she said that she would not want to live like that. In addition, while attending the funeral luncheon for Michael's grandmother she reportedly said, "if I ever go like that just let me go. Don't leave me there. I don't want to be kept alive on a machine." And her sister-in-law testified that, after watching a TV movie in which a man following an accident was in a coma, Terri said words to the effect that she wanted it stated in her will that she would want the tubes and everything like that taken out if that ever happened to her.

The judge found that this testimony regarding the statements that she had reportedly made on different occasions were a credible indication of her intentions as to what she would want done under her present circumstances. He also ruled that those statements met the legally required standard of clear and convincing evidence, and that if Terri could make her own contemporaneous decision, she would choose to discontinue the tube feedings. In addition he found that Terri was undoubtedly in a PVS without hope of ever regaining consciousness and therefore capacity. This ruling was issued on February 11, 2000. That was not the end of the legal battle; five more years of litigation ensued before the PEG was withdrawn for the last time. She died, at age 42, 15 years after her cardiac arrest.

How are we to understand the meaning of statements purportedly made about life-sustaining treatments approximately 20 years earlier, when Terri Schiavo was a young woman in her mid-20s? We reflect on this question from the perspective of two small exploratory studies that considered the meanings of previously made expressions concerning desire for hastened death.

The Coyle study (Coyle & Sculco, 2004), through a series of narrative interviews with advanced cancer patients who had expressed a desire for death to come more quickly or to be hastened, explored the meaning and uses of such expressions in this population. What they found was these expressions commonly fluctuated depending on the current situation (physical, social, psychological, and spiritual) and that sometimes a situation that was most feared became acceptable once it had happened. The Schwarz study (2003), also through a series of narrative interviews but this time with nurses who had been asked for assistance in dying by capacitated patients, explored how these nurses interpreted and understood the meaning of such requests and how that understanding determined the nature of their responses. Schwarz found that for the nurses in this study, the process of understanding the meaning of these requests occurred over time, and the meaning of the requests for assistance in dying was often hidden or masked by layers of language. It might also be noted that Schwarz, unlike Coyle but similar to the Judge in Terri Schiavo's case, was removed from directly hearing the patients' words. In the Schwarz study the patients' spoken requests were initially filtered through the participating nurses, who first heard, then tried to understand and respond to the meaning of the request. At a later time, that experience of being asked and responding to requests for assistance in dying was described in detail to the researcher. Although Schwarz was able to ask the participating nurses for clarification about aspects of these patients' experiences, she was unable to determine whether these patients would have told the same story.

The Schiavo case was very different from both these study populations. In the Schiavo case you have a situation where a young woman who is essentially healthy has a totally unexpected catastrophic event that leaves her in a PVS and whose previous expressed desires were uttered in words that were "generic" at best, and are subsequently used as *the* determining factor as to whether her tube feedings should be stopped or maintained. How comfortable should we be with our use of previously made statements as the deciding factor *now*—in an action that will result in the death of an individual? The contextual reality of the current situation may be vastly different from the one that was initially described or considered. In the Schiavo case, the question would be the same if previously made statements had resulted in her being maintained in a PVS rather than her being allowed to die.

What moral weight, if any, ought we to attribute to previously made statements when a decision must now be made about whether to continue or withdraw life-sustaining treatment? Are such statements better than nothing or do they tie the hands of surrogate decision makers who might otherwise make a different decision based on contemporaneous clinical findings, recommendations of a health care team, and a judgment about what would be in the now incompetent person's best interests.

When a surrogate decision maker uses the "best interest" standard, the goal is to protect the incompetent person's well-being by objectively weighing the benefits and burdens of various treatments and alternatives to treatment, including considerations of pain and suffering and by evaluating the possibility of restoration or loss of functioning. It is considered "inescapably a quality-of-life criterion. Those applying the best interests standard should consider the formerly autonomous patient's preferences, values and perspectives only as far as they affect interpretations of quality of life, direct benefit, and the like" (Beauchamp & Childress, 2001, p. 102). This "best interests" standard is also known as the "reasonable person" standard—what a reasonable person would most likely want in the same circumstances. Because patients who are permanently unconscious are unaware of benefits and burdens, those applying a *reasonable person* standard to patients in this condition must consider other benefits to continued use of life-sustaining treatment such as the possibility that the diagnosis of irreversible coma is incorrect and the patient might regain consciousness. Thus the question would be whether a reasonable person in the patient's circumstances would find that this benefit, and the benefits to the patient's family or close friends (e.g., pleasure in caring for the patient or the meaningfulness of his/her continued existence) are outweighed by the burdens on those loved ones (such as financial cost or emotional suffering; Hastings Center, 1987).

In the following discussion, selected findings from the studies by Coyle and Schwarz will be used to illustrate the difficulty in interpreting the meaning of statements made by patients about a desire for hastened death in the setting of terminal disease. Such interpretations would seem doubly difficulty when a statement is made casually to family and friends in response to a particular situation involving others, about personal preferences regarding end of life care.

The Coyle study (Coyle & Sculco, 2004), involved a series of 25 semistructured interviews with seven individuals living with advanced cancer who were followed by a Pain and Palliative Care Service at a cancer research center and had at least once expressed a desire for hastened death. The intent of the interview series was to untangle the meaning and uses of the expression of desire for hastened death made by these individuals. The interviews were carried out in a variety of settings—tertiary cancer center, terminal care facility, home, student residence, outpatient clinic, and rehabilitation center. The patients had a variety of different cancers and were fairly evenly divided between male and female, and the majority were professional Caucasians with an age range from the mid-40s to the mid-70s. The data was coded, individual themes analyzed, and common themes identified.

Most of the expressions of desire for hastened death were made in response to fear of the future and what it would bring in relationship to pain, debility, dependency, and burdening the family financially, physically, or emotionally. These expressions were related to both concerns about the individual's personal suffering and well-being and concerns about the well-being of the family—both concern for self and concern for others. The expression of desire for hastened death appeared to be used by these patients as a tool of communication to both express these fears and to get their needs met. In these individuals it did not appear to be a literal request. Once their fears were expressed it was possible to have them addressed in a very concrete manner by staff and family. However, two individuals were deeply concerned about how they would be remembered. They did not want to be remembered as debilitated, dependent, nonfunctioning individuals who were "able to contribute nothing" to society. Both removed themselves from potentially life prolonging therapy in order that their death would "come more quickly."

The Schwarz study (2003), involved open-ended discussions with each of the 10 nurses who, at least once, had been asked by a decisionally capable patient for assistance in dying. Each initial discussion lasted several hours and was followed by a subsequent discussion at a later time that allowed for questions to be answered and clarification provided. Five participating nurses worked in home hospice and three worked with persons with AIDS; these eight nurses heard requests for aid in dying rather often. The remaining three nurses who worked in critical care and neurology described these requests as unusual events in their professional lives. Although in several cases the experience of hearing the request had occurred many years earlier, these nurses seemed able to recall and describe their experience with great detail. These detail included the patient's clinical circumstances, how the nurses understood the "meaning" of the request, and given that understanding, their response to the request.

The concept of "assistance in dying" was not research-defined; each nurse described its meaning by the stories they told of their experiences. In all cases the nurses' initial response to hearing such a request was to begin actively exploring what the patient actually meant by the request. The process of searching for meaning unfolded over time as they sought to identify and remedy any unmet needs. *Thus in both studies initial attempts were made to understand what the patient actually meant by their spoken request.*

Although nurse participants in the Schwarz study indicated that some of the patients' requests for assistance in dying continued over time and were unchanging, most of those who initially asked for help in dying subsequently changed their minds or withdrew the request once they received good palliative end-of-life care. The nurses also reported that when patients' requests for assistance in dying persisted, the patient's reason for the request almost always involved aspects of suffering that included insults to the patient's sense of self, inability to pursue meaningful activities, and unacceptable deterioration in quality of life. Participating nurses acknowledged that such symptoms of suffering were extremely difficult to relieve.

Although the context of Terri Schiavo's reported statements, the words themselves, and the judicial interpretation are quite unlike the circumstances in which the participants of the Schwarz and Coyle studies spoke about their wish for a hastened death to bedside nurses and a nurse researcher, findings common to both studies appear relevant to the central question: Is it ever possible to have any real (accurate) understanding about what is meant by statements that seem to suggest desires about death unless those statements have been thoroughly explored through a process that occurs over time.

## USE OF ADVANCE TREATMENT DIRECTIVES—WHAT WORKS AND WHAT DOES NOT

There is a growing consensus among health care clinicians, bioethicists, and legal scholars that advance treatment directives, particularly written or oral instruction directives, often do not achieve their intended goal. Despite the hope that a completed advance directive would ensure that patients' treatment preferences are honored, and notwithstanding a vast effort to encourage citizens to complete such documents, only 20%–30% of eligible adult Americans have one, and these completed documents have a limited effect on the actual end-of-life treatment decisions (Hickman et al., 2005). Hickman and colleagues note that instructional directives are grounded in the assumptions that individual/personal autonomy is the driving force in end-of-life decision making for most people in this country, when in fact many Americans as well as individuals from non-Western cultures employ a broader social network as the basis for treatment decisions.

Although the appointment of health care agents or proxies is the recommended means of ensuring that one's treatment preferences will more likely be honored, this form is not without difficulty. Ditto and colleagues (2001) found that family members' predictions of what the patient would want were correct less than 70% of the time, and families were two to three times as likely to make errors of overtreatment as undertreatment, for example, okaying life-sustaining treatments the patient would not have wanted under the circumstances (Ditto et al., 2001). Meisel and colleagues (2000) similarly note that, if there are differences in family opinion about treatment choices, the wishes of the family member advocating a more aggressive medical response are more likely to be followed, even if not based on evidence of patient preference. Meisel et al. state that this default response in favor of aggressive treatment occurs because clinicians believe that the legal risks of continuing treatment are less than those of stopping treatment; this default position is greatest when the patient lacks capacity but is not permanently unconscious and has been unclear about his/her wishes.

Because surveys of Americans indicate that almost 80% of people in the United States say they would want their families to be allowed to choose against a feeding tube or any other kind of treatment if they were in a vegetative state, some commentators recommend that persons who want artificial nutrition and hydration administered if they became permanently unconscious ought to assume responsibility for completing an advance directive requesting that treatment. Not giving such treatment would otherwise become the default position.

Another concern associated with the use of previously made oral or written statements as a guide for contemporary clinical decisions is known generically as the "former decision" problem or the "former person" problem. Because incapacitated persons are unable to understand or reaffirm their previous written statements—or to expand on the meaning or significance of previously made oral statements—a number of scholars argue that such previous instructional directives may be challenged as no longer representing the contemporaneous wishes of incapacitated patients and should be disregarded in favor of the patient's current best interests (Dresser & Robertson, 1989). Some commentators believe that many of the questions asked about the Schiavo case are the wrong questions. Eric Cohen, a resident scholar at the Ethics and Public Policy Center, opined that "we have asked what she would have wanted as a competent person imagining herself in such a condition, instead of asking what we owe the person who is now with us, a person who can no longer speak for herself, a person entrusted to the care of her family and protection of her society" (Cohen, 2005).

Concerns have also been expressed by members of the current President's Council on Bioethics about the moral utility of prior oral statements made by currently incapacitated persons. They noted that because relatively few people go through the formalities of completing a written advance directive, oral statements are the most common instruction directives available to caregivers.

Relatives and clinicians sometimes consider a person's past remarks about the kind of treatments or quality of life that would be acceptable as relevant information in making medical decisions on that person's behalf. Like written instruction directives, oral directives vary in specificity and precision. They can also be more difficult to evaluate because the seriousness of the speaker's intent is not always obvious. For example, statements made in response to watching a film or visiting an ailing relative may or may not be well considered, and their significance for future caregiving decisions is often hard to judge (President's Council, 2005).

The President's Council on Bioethics concluded the following about written advance directives: "Not only are living wills unlikely to achieve their own stated goals, but those goals themselves are open to question. Living wills make autonomy and self-determination the primary values at a time of life when one is no longer autonomous or self-determining, and when what one needs is loyal and loving care" (President's Council, 2005).

So back to the original question: Can we know with certainty what Terri Schiavo would have wanted? Probably not. How are we to understand the meaning of statements purportedly made about life-sustaining treatments approximately 20 years earlier when applied to the current situation? How comfortable should we be with our use of previously made statements as the deciding factor *now*—in an action that will result in the death of an individual? The Schwarz and Coyle studies indicate that individuals frequently changed their minds when in situations they previously feared the most, that adaptation takes place, and what was most feared becomes acceptable, tolerable. However, the studies also indicated that this is not always the case, and that some individuals persist in their desire for hastened death. Ms. Schiavo, who was now in a persistent vegetative state without hope of ever regaining consciousness, was without capacity to reflect on this. All we have to go on are the judgments of those who supposedly knew her values best, loved her best, and would presumably want for her what she would have wanted for herself. It was for them to say whether her previously made statements about measure not to be taken to preserve life would reflect her contemporaneous wishes. That her parents and husband had such opposing views resulted in the final decision—purportedly reflective of what she would have wanted—made by strangers in the Courts of Law. Yet who would Terri have wanted to make those decisions for her?

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