Case 9—When Parents Contest an Adult Child's Advance Directive

9

AH was a 25-year-old woman who had been admitted to the intensive care unit of a large teaching hospital, despite being under the care of the local hospice agency. She had been diagnosed with end-stage cardiomyopathy (weakening of the heart muscle) and currently had an ejection fraction of 10% (normal range: 55–70%). AH made sure the attending physician knew she had an advance directive that specified her care was to be limited to comfort measures only, with the added provision that she did not want to be on a ventilator or to be maintained on a feeding tube for more than 30 days, which contradicted her preference for comfort measures only. This concession resulted from an apparent disagreement with her mother, who wanted her daughter to agree to life-sustaining treatment indefinitely should it become necessary.

AH lapsed into a comatose state shortly after admission to the hospital, and required ventilator support as well as a feeding tube for artificial nutrition and hydration. Her parents, who were divorced, were informed of her poor prognosis and were reminded of her advance directive which specified time limits on life-sustaining treatment were it to be initiated. AH's father was an uneducated man who wanted to honor his daughter's wishes and remove her from life support after 30 days. AH's mother, who had a history of schizophrenia, wanted her daughter kept alive indefinitely and hired an attorney who had previously represented Terri Schiavo's parents.[1]

AH's condition did not improve during the 30 day trial of life sustaining treatment. On the evening of the 29th day of ventilator and feeding tube support, the attorney who had been hired by AH's mother came to the hospital, placed a note in the medical chart indicating that she had the authority to revoke AH's advance directive, and attached her business card to the chart. (This case predated the use of electronic medical records.) At this point, a physician known for his commitment to honoring patients' advance directives rotated onto the unit. He was not intimidated

L. A. Roscoe and D. P. Schenck, *Communication and Bioethics at the End of Life*,
https://doi.org/10.1007/978-3-319-70920-8_9

by the attorney's note, despite her involvement with the infamous Schiavo case, and urged the hospital administration to go to court if necessary to ensure his patient's wishes for discontinuation of treatment after 30 days.

A family meeting was held with the attending physician, nurses and social workers on the unit, ethics committee members, and AH's parents. The attending physician strongly endorsed allowing AH to be removed from life support according to the provisions of her advance directive, which was supported by all medical and ethics committee staff members, as well as by AH's father. Her mother disagreed and threatened to bring legal action against the hospital if life support measures were discontinued.

AH's mother and her attorney filed suit against the hospital. During the subsequent court hearing, the mother's mental instability was notable. She argued that the signature on her daughter's advance directive had been forged, even though she also conceded that it matched her daughter's recent signatures on consent forms signed upon her hospital admission. AH's mother also produced a note on scraps of paper taped together that stated her daughter wanted her advance directive rescinded, and that she wanted her mother to make all medical decisions for her should she be unable to speak for herself. This note had an illegible signature AH's mother claimed was her daughter's signature. The attorney also stated that AH had withdrawn her advance directive when she was recently admitted to the hospital where she was now receiving treatment. AH's father was in attendance and spoke on behalf of his daughter's wishes, but he had not retained legal counsel and did a fairly ineffective job of describing what he thought should be done to keep his daughter comfortable while withdrawing life support.

The hospice representatives testified that AH was competent to make her own medical decisions when she was admitted to hospice and that she had executed the current advance directive upon admission to their care. They weakened their case, however, when they admitted that the original advance directive had been lost, and that while they believed the present document was similar, they could not testify that the two documents were identical. The judge who was presiding over the hearing announced that she "refused to be associated with another Terri Schiavo situation," and that life supportive care must be continued until the next hearing, which she then delayed for three months. She also named AH's mother as her guardian, despite what appeared to most observers as her erratic behavior, mental instability, and previous diagnosis of schizophrenia.

Meanwhile, the intensive care nurses and other staff members were forced to provide continued life support and care to AH that they believed she did not want. The consensus of the intensive care team was that continued life support for AH was futile, that her advance directive should be honored, and that life support should be withdrawn according to her stated preferences. Prior to the next scheduled court hearing, AH coded and died, despite the best efforts of the medical staff to revive her, having been maintained on a ventilator and feeding tube for three months.

Discussion Questions

1. The Terri Schiavo case presented a chilling precedent for end-of-life cases. Ten years after her death there were still those who felt her husband was right to advocate for what he believed (and convinced the court again and again) were her wishes not to be maintained on life support, and those who felt strongly that Terri was a disabled woman starved to death against her parent's wishes. Does the Schiavo case present a useful precedent for making ethical judgments in AH's case?
2. What are the pros and cons of seeking a court hearing in a case such as this? Are there alternatives that hospitals and physicians might pursue in order to ensure that patients' wishes can be followed without having to go to court?
3. "Slow code"[2] refers to situations where the "crash cart" team in a hospital or other medical center purposely responds in a slow or incomplete manner to a stat call to assist a patient in cardiac arrest; although rare, it may be done when CPR is judged to be of no medical benefit. Is this ethical?
4. Advance directives can be helpful under the right circumstances, and ineffective in others. How might advance directives be improved to avoid situations like this?

A Bioethicist Responds

Given the particulars presented in this case, it seems fairly astonishing that AH should end up in the situation she did at the moment of her death. First, the fact that this occurred in the same state as the Schiavo case means, according to Florida State Statutes, that both of AH's parents should have had equal standing as legal surrogates; furthermore, it occurred less than ten years later. Second, a significant irregularity appears to have taken place on the part of the attorney hired by AH's mother, one that goes unchallenged. Third, the judge appeared to have been more interested in avoiding a difficult family member and a potentially troubling public relations problem than in acting to do a right and good thing for an incapacitated patient. And, finally, the professionals caring for AH were destined to become frustrated when their combined skills, knowledge, experience and perspectives on situations such as those surrounding AH were effectively "high-jacked" by persons not having benefit of the same.

Admittedly, we do not know who AH might have named as surrogate, or surrogates, in her original advance directive, which the hospice reportedly had lost, so it is possible that her mother could have been named as her only surrogate. Nonetheless, the mother's determination to contradict AH's clearly stated oral preferences to her physician, which were corroborated in her advance directive, combined with her own history of schizophrenia, and her having hired an attorney who at one time had represented Terri Schiavo's parents, are problematic issues from the very beginning. Complicating the situation even further was this attorney's placement of a note in AH's medical chart claiming that she had the authority to revoke AH's advance directive. It is unclear where, in Florida Statutes at any rate,

such a claim might be supported, and there is no indication in the case report as to why the judge would accede to this action. Moreover, it is irregular, to say the very least, for anyone outside those charged with direct, or delegated, care of a patient to add something to a patient's chart absent permission. The remaining description of the court hearing is equally troublesome, raising yet more puzzling questions about the judge's action, or rather, inaction in this case.

For whatever reason, the judge has chosen the easy way out here. It would appear that she had gleaned enough from the testimony of the medical team that AH would not survive an indefinite period of time, and so she delayed the case for three months, no doubt hoping that AH would succumb in the meantime. She obviously achieved her purpose while also sparing herself having to make any difficult decisions. It demands little imagination to suggest that she might also have thought she would be doing relatively little harm (not least to herself!) in making this choice, especially insofar as AH was in what was described as a persistent vegetative state. Yet she has, in fact, done a great deal of harm in that she has clearly not supported AH's right to have her advance directive followed, given no clear indications to the contrary that would, on the basis of valid evidence, justify an appeal to the standard of substituted judgment, or, failing that, the best interests standard. Moreover, significant harm is indeed done to the physicians, nurses and others who cared for AH by virtue of misuse of their time and skills, as well as offense to their professional integrity; to an already burdened health care system with limited resources and where continued life support had been judged to be futile by the intensive care team; and, most of all, to a patient who had indicated she did not want the treatment being administered, her lack of awareness notwithstanding.

AH's new physician, who came on the case at about the same time as the appearance of her mother's attorney, would have been entirely justified in discontinuing life support after the 30 days period had ended, and he was entirely right not to have been intimidated by the attorney's note in the chart, or the fact that she had worked on the earlier Schiavo case. It is very unfortunate, however, that the attending physician urged the hospital to seek the court's help in resolving what never should have been all that difficult a decision but which became complicated and was made potentially very troubling because of the weight of a notorious precedent case and the trauma suffered by many involved. Yet it is perhaps also unsurprising that he did so, or that he may have had no choice but to do so: hospitals generally have their risk management offices work closely with their ethics committees, often with an attorney representative of that office serving as *ex officio* member of the committee, and risk management could well have insisted the issue be referred to the court if for no other reason than to protect hospital interests.

What then happened, in effect, was that a person or entity (judge, court) other than the one with the true moral authority for the decision to discontinue treatment usurped that authority, chose poorly in making the decision (effectively no decision at all, as indicated above), did far more harm than good to all, and cast herself in a less than distinguished light in the process. While it is always easy to second guess after the fact, perhaps one approach the attending physician might have taken in attempting to reclaim some legitimate control over the situation, once it had become

tied up in this judge's court, might have been to request an emergency review by a higher authority, a chief judge perhaps? Given the long shadow of the Terri Schiavo case, however, and particularly in the same geographic area where some of the same central characters were still living and working, nothing suggested by the legal system might have carried much weight.

The Terri Schiavo case[1] occupied the courts, newspapers, and ethics committees for 15 years in West Central Florida, and eventually became an international news story that involved the Supreme Court (they declined to hear the case), the Pope, the President of the United States, and the Governor of Florida. Her husband maintained, and was supported in every court hearing, that his wife would not want artificial nutrition and hydration to keep her alive in a persistent vegetative state, while her parents maintained that their daughter would never choose to starve herself to death, regardless of her condition. The judges and attorneys involved in the case were subject to death threats, harassment, and negative publicity. Terri Schiavo did not have an advance directive and had no knowledge of her medical condition; she lapsed into a coma and eventual vegetative state from which she never recovered and of which she was never aware.

AH's situation unfolded a few years after Terri Schiavo's death and in the same general geographical area, and no one wanted to be involved with another case in which another young woman would die because of legal action. So although AH's situation was markedly different in that she had managed a serious chronic illness for some period of time and had a valid advance directive, the evocation of Schiavo was enough to convince the judge involved in AH's case to prolong the proceedings until her death, rather than preside over what she felt might be "the next Schiavo case." Prolonging the next hearing is ethically questionable, but even more so was the appointment of AH's mentally unstable mother, who had made her intentions to thwart AH's advance directive abundantly clear.

The Schiavo case was a momentous one, and it became something of a political and religious issue attracting many impassioned voices. It is understandable how the judge in the AH case would thus be chary of presiding over "the next Schiavo." Prudence, therefore, also demands that a case such as Schiavo be used judiciously, along with other precedent cases, when attempting to resolve new ones. This is not to imply that Schiavo, or any other high profile case, should ever be viewed as so intimidating or as so exceptional that it be set entirely aside and not included with other precedent cases, regardless of how it may tend to reshape the paradigm, provided it is appropriate for inclusion with similar cases. It is to suggest, however, that those factors which might be seen to have attracted the stark attention to Schiavo, such as the political and religious debates that became partisan and rancorous at times, not to mention the death threats against the local judge who had ordered Terri Schiavo's feeding tube be withdrawn, be carefully "bracketed," or set apart insofar as possible, in order to promote an optimal, reflective and analytical response to the case at hand.

A Health Communication Scholar Responds

Law and ethics, as we mention in several of these case chapters, are different, but are hopefully able to work together to protect patients and to help ensure they get the medical treatment and legal protection that is most in line with their beliefs and preferences and state and federal statutes. The law failed in the Terri Schiavo case because it was not able to adequately address a situation in which a young adult patient's parents and spouse were so at odds. Even though Florida's end-of-life statute clearly identified Terri's husband (who was also appointed as her guardian) as her legal decision maker, it failed to provide guidance for situations in which a patient's parents disagreed and utilized the media and politics to press their point of view. The Florida statute assumes a fairly high degree of family harmony, which was certainly missing in both the Schiavo case and the case described here. The Schiavo case also occurred during a particularly conservative time in our nation's history, which also featured a U.S. President and Florida Governor who were brothers, and a Pope (John Paul II) who himself used a feeding tube at the end of his life.

All state laws governing end-of-life decisions must take the federal Patient Self-Determination Act (PSDA) of 1991 into account. The law requires hospitals, nursing homes, home health agencies, and health maintenance organizations (HMOs) that receive federal funds to routinely provide information to patients about advance directives at the time of admission. Advance directives allow a patient's autonomous choices about the medical care they desire to be maintained after they lose the ability to make or communicate their own health care decisions. Health care agencies must also develop policies and procedures to ensure patients' health care directives are followed; in Florida, health care providers who provide care in accordance with a patient's advance directive receive immunity from legal action. Most states, Florida included, suggest templates for advance directives that will be familiar to the health care facilities in their state or region, and it is to the patient's advantage to have an advance directive that appears thoughtful, official and complete. The scrap paper substitute that AH's mother produced in court should have been dismissed as fraudulent, but patients are not required to have advance directives that adhere to a specific format. A legally acceptable advance directive can be written (neatly) on paper, signed by the patient, and witnessed by a notary. A written document is more durable, but patients are also allowed to use oral statements as evidence of their advanced care planning and treatment preferences. In Florida, advance directives are defined as "a witnessed written document or oral statement in which instructions are given by a principal or in which the principal's desires are expressed concerning any aspect of the principal's health care."[3]

According to Florida law, a person's advance directive comes into play when they are unable to communicate their preferences for treatment, either because they are in a *terminal condition* (caused by injury, disease, or illness from which there is no reasonable medical probability of recovery and which, without treatment, can be

expected to cause death); an *end-stage condition* (an irreversible condition caused by injury, disease, or illness which has resulted in a progressively severe and permanent deterioration, and for which treatment would be ineffective); or a *persistent vegetative state* (a permanent and irreversible condition of unconsciousness in which there is the absence of voluntary action or cognitive behavior or any kind, and an inability to communicate or interact purposefully with the environment) (Cranford 1988; Wade and Johnston 1999). Patients who have not been diagnosed with one of these conditions, or who are able to make their own decisions, are not held to the preferences outlined in their advance directives. For example, a patient who is expected to recover from his or her illness, disease or injury is likely to receive medical treatment regardless of instructions provided in their advance directives, and generally even if their surrogate or proxy decision maker demands that care be withdrawn. The preferred course of action in these cases is generally to treat the patient to the point where they are able to direct their own care. And patients who are competent to make and communicate their own treatment preferences can always override their written instructions even if they eventually meet the prognostic requirements for their advance directives to take effect.

A patient's advance directive, like AH's, is likely to indicate under what circumstances, if any, life-prolonging procedures are desired. Life-prolonging procedures specifically include not only ventilator support, but "any medical procedure, treatment, or intervention, including artificially provided sustenance and hydration, which supports, restores, or supplants a vital function."[3] Patients are free to choose the procedures and circumstances that conform to their values and preferences. The law states "every competent adult has the fundamental right of self-determination regarding decisions pertaining to his or her own health, including the right to choose or refuse medical treatment." It recognizes that life-prolonging procedures may result in "a precarious and burdensome existence," and that competent adults can make an advance directive instructing his or her physician to "provide, withhold, or withdraw life-prolonging procedures." As indicated in the case report, AH's advance directive did state her willingness to a 30-days trial of life supportive measures, after which they should be discontinued.

The Florida statute also outlines a hierarchy of proxy decision makers who can serve as a patient's decision maker, beginning with a legally appointed guardian, and then spouse, and ending with a close friend or licensed clinical social worker. The law further provides guidelines for reviewing the decisions made by a patient's proxy or surrogate decision maker (respectively determined by law, or by the patient's designation). These guidelines suggest that judicial review is appropriate if a proxy or surrogate makes decisions that are not in accord with a patient's known desires, has abused their powers or failed to discharge their duties, or if the patient's advance directive is ambiguous. It is not clear whether AH nominated her mother as her sole surrogate, or whether she intended her advance directive to dictate her care without much need for interpretation or advocacy.

There are problems with advance directives, and even well-crafted legislation can fail to address the practical realities of health care, or the twisted logic of human

relationships. Advance directives can be lost, be incomplete or contradictory, be irrelevant to the situation at hand, or be contested by family members. It is impossible for a static document to communicate effectively all of the nuances of personal preferences for medical treatment, or to adapt to the exact conditions at hand. Laws can assume harmonious family relationships where they do not exist, and they can fail to account for the current reality in which everyone is entitled to their day in court. It is clear in this case that AH was in an end-stage and terminal condition and was perhaps soon also to be diagnosed as being in a persistent vegetative state as well (one need not be diagnosed as being in all three of these categories; just one will suffice). Her advance directive was completed upon her admission to a health care facility—a hospice agency—appropriately signed and witnessed, and then unfortunately lost. AH was also careful to specify the exact terms of her willingness to endure life-sustaining treatment. It would have been reasonable and perhaps even expected under the conditions of her hospice admission that she forego all life-supportive measures, and perhaps also to investigate whether having do-not-resuscitate status would further support her treatment preferences.

Many of us, however, may find ourselves in circumstances in which we make concessions to our loved ones, and AH did so by acknowledging her mother's disagreement with her refusal of life support. To allow her mother time to grieve, perhaps, or to say goodbye, AH agreed to no more than 30 days of ventilator and other life support; surely she did not intend for this concession to provide an opening for her mother to pursue legal action. As best as we can determine, AH had an advance directive that specified limits to her care, and she met the conditions under which it should be implemented. But similar to the Schiavo case, family disagreements circumvented the application of good law, sound ethical judgment, and expert medicine.

We might be tempted to say that AH's extended period of life support was necessary for her mother's grieving process, and that it did not significantly impact her due to her unconsciousness. Although many may feel AH's mother acted inappropriately, we must also keep in mind the particular difficulties of end-of-life decisions for chronically ill children who live until adulthood. AH was a chronically ill child whose mother had been making medical care decisions for her, at least for the first 18 years of her life. We are not privy to the process the two used to make medical decisions when AH was younger, but we do know their joint efforts resulted in keeping her alive to age 25. We also know nothing about the state of their relationship when AH suffered her final illness. AH's agreement to a trial of life support at least indicates concern for her mother's feelings and preferences. The process of assuming the right and responsibility to make her own decisions, about her medical care and other issues, was complicated by her long-standing illness. Her mother's serious mental illness also produced another difficulty in securing a smooth transition from parental decision-making to her own. Family dynamics are not accounted for in state laws governing end-of-life decisions, and the Florida

statutes are no exception. Advance directives can be effective in specifying the treatment preferences of an incapacitated person, but they cannot completely substitute for a person's ability to speak for him- or herself or negotiate a compromise with a family member.

Despite the grief of family members, we are still entitled to have our wishes honored in spite of our incapacity, perhaps even more so. We also have to be mindful of the toll that providing futile or unwanted care exacts on nurses, physicians, and other health care providers, who experience moral distress and burnout when their job requirements are at odds with their moral judgments. What we can say about the hospice agency that "lost" AH's original advance directive and inadvertently supported her mother's off-base judgments is difficult to determine. We can only hope that the people we entrust to care for us, including our family members, our medical providers, and worst case, our legal system, will have our best interests at heart and will competently perform in their respective roles. All of these individuals, with the exception of the physician and the hospital who were willing to go to court on AH's behalf, failed her.

Notes

[1]Terri Schiavo was a young woman who was maintained with a feeding tube in a persistent vegetative state for 15 years while her husband and parents argued about her wishes for life-sustaining treatment. After trying aggressive and experimental treatment and rehabilitation for several years, her husband, Michael, maintained that Terri would not want to be kept alive in her condition with no hope of recovery; her parents argued that their daughter was a good Catholic who would never do anything intentionally to end her life. This case was the most litigated end-of-life case in history, and it ended in Terri's death in a hospice house after her feeding tube had been removed and reinserted three times. It was also one of the most highly publicized, emotionally charged and politicized cases in the history of American biomedical ethics. Much has been written about it, some of which lacks completeness and total objectivity. One starting point for a beginning look at Schiavo, and one which can be said to lay out the pertinent issues of the case as objectively as possible, without taking sides and with no hidden agenda, is Caplan, Arthur L., James. J. McCartney, and Dominic J. Sisti. 2006. *The Case of Terri Schiavo: Ethics at the End of Life*. New York: Prometheus Books.

[2]**Slow code** refers to the practice in a hospital or other medical center purposely to respond slowly or incompletely to a patient in cardiac arrest, particularly in situations where CPR is of no medical benefit.

[3]Florida State Statutes, Chap. 765. http://www.flsenate.gov/Laws/Statutes/2013/Chapter765/Part_I.

References

Cranford, Ronald. E. 1988. The persistent vegetative state: The medical reality (getting the facts straight). *The Hastings Center Report* 18: 27–32. https://doi.org/10.2307/3562014.

Wade, Derick T., and Claire Johnston. 1999. The permanent vegetative state: Practical guidance on diagnosis and management. *British Medical Journal* 319: 841–844.