



CAN THE HEALTH CARE SYSTEM EVER SAY NO?

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INTRODUCTION

Historically, the title question has been a topic of fervent debate. Albeit relegated to academic discussions for many years, it has again entered intense public discourse. With continued advances in medical technology that prolong life, along with the legislative push to reform our health care system, the ability of the system to withhold or withdraw care despite family objections has certainly captured the public's attention. Whether the discussion centers on rationing care, on the so-called "death panels," or on the cost of elaborate care in the last six months of life, the ultimate question is: "Can the health care system ever legally refuse to provide care?" The genesis of this question is the inherent conflict between the right to self-determination and the right of the medical community not to provide medical care that is medically and/or ethically inappropriate. Naturally, this tension is at its peak when families are faced with end-of-life care decisions and the medical science is uncertain.

I'll begin by answering the question posed above: Yes, as a general principle, the health care system can refuse to provide care. However, it's not so simple. Intense debate is generated by the lack of concrete guiding principles to define the circumstances in which the health care system can refuse care.

RIGHT TO DEMAND TREATMENT?

One certainly would not find it improper or ethically inappropriate for a physician to refuse to implant a pacemaker in an otherwise healthy 25-year-old man just because the young man demands the implant. Likewise, one cannot walk into a hospital and force a physician to perform a procedure, such as gall bladder surgery, that would provide no benefit to the individual, for which the individual is not a candidate, and which is not consistent with current medical standards of care. Similarly, a cosmetic surgeon can refuse to perform a rhinoplasty, breast augmentation surgery, or any elective operation if, for example, the surgeon feels it unnecessarily jeopardizes the safety of the

individual, if the individual lacks the financial resources to pay, or if the surgeon simply refuses to accept any new patient for elective care, without even offering a reason. So, clearly, the health care system can refuse to treat individuals. But, those are extreme (and common sense) examples. What about cases where a patient is in a vegetative state and on mechanical support and the medical team recommends withdrawing support, yet the family demands continued care in hope of some miraculous recovery?

The Code of Ethics of the American Medical Association addresses the relationship between a physician who feels treatment is inappropriate and the patient who nonetheless demands to be treated.¹ In essence, the Code of Ethics states that a physician has no obligation to provide medical treatment that will have no reasonable chance of benefitting the patient. It continues by stating that a physician may justify denial of medical treatment on open, sound ethical principles and acceptable standards of care. Interestingly, it recommends avoiding the concept of medical futility as it cannot be meaningfully defined. Although helpful in laying a most basic foundation, the Code of Ethics fails to provide legally meaningful guiding principles to the medical community to resolve disputes between families and the health care providers regarding end-of-life treatment.

UNSETTLED LEGAL FOUNDATION

From a legal standpoint, courts have not consistently favored a patient's right to self-determination over the freedom of the medical community to refuse to provide medically inappropriate care. In most cases, courts defer to the current standard of care and to hospital policies to facilitate resolution of disputes between physicians and families, but they fall short of specifically authorizing a physician or hospital to withdraw care over families' objections. Courts have recognized that physicians cannot be forced to provide care that is not beneficial. However, they have failed to announce concrete standards or consistent

principles to guide the medical community to resolve disputes between it and patients (and their families). Most courts recommend that a physician who is uncomfortable providing continuing care that is potentially ethically inappropriate should transfer care to a physician willing to continue care. Still, this recommendation presumes that another physician or hospital is willing to take responsibility in a case that is fraught with ethical challenges. Similarly, the majority of state legislatures have failed to offer principles or guidance to the medical community on how to resolve disputes between physicians and demanding families regarding what they consider to be medically-inappropriate care. A handful of states, notably Texas², have passed state laws establishing rules that hospitals, physicians, and patients must follow to resolve disputes concerning potentially futile care. Although courts, and in some cases, state legislatures, have shown a willingness to recognize circumstances in which the health care system can refuse to continue care that is not beneficial, recent events indicate that the tide may be turning.

RECENT COURT CASES FAVORING PATIENTS' RIGHTS IN END-OF-LIFE CARE

A recent case in New Jersey, which is currently in the appeals process, surprised many in its decision to allow a patient's daughter (who was appointed guardian) to reject the physician's and hospital's recommendation to withdraw care.³ The patient, in addition to suffering from malignant thymoma and renal failure, developed anoxic encephalopathy after extubation. He became unconscious, was placed on a ventilator, continued to receive dialysis, and required a feeding tube. After a year, the physician informed the family that the patient was in an irreversible vegetative state and recommended that mechanical support be discontinued. The patient's daughter refused to accept the physician's recommendation because the family believed the patient still had a chance to recover, and regardless, the patient was once an active gentleman and would not want to give up. The family filed suit to prohibit the hospital and physicians from withdrawing support. They argued that the medical community cannot, on its own volition, discontinue support. The family offered evidence that, if able to communicate, the patient would want everything done. The hospital and physicians argued that maintaining the patient on support was unethical and medically inappropriate because there was no chance of recovery. Further,

medical providers cannot be forced to continue treatment that poses no benefit to the patient. The court decided in favor of the patient's daughter indicating that, as the patient's surrogate decision maker, only she can direct the withdrawal of support. In essence, the court held that a patient's right to self-determination is paramount to the medical community's right to be free from providing care that may be medically inappropriate. The hospital appealed the decision of the court, so it will be interesting to see how this case is finally decided.

A case from Washington, DC similarly garnered national attention when the hospital petitioned a court to authorize it to remove mechanical support on a patient who was declared brain dead.⁴ The patient, a teenager who had a malignant brain tumor, was declared brain dead following numerous neurological tests. The patient's family, Hasidic Jews, refused to accept the determination of brain death, as they adhered to the particular Rabbinical view that only recognizes death when an individual's heart and lungs cease to function. Since mechanical support maintained the patient's heart and lungs, the family refused to accept the determination of death. The hospital asked the court to authorize it to remove support since the teenager was declared legally dead and was unnecessarily consuming scarce resources. During the court proceedings the patient passed away, and the hospital ultimately withdrew its petition. However, the fact that a case in which a patient was declared dead made national headlines provides evidence, although anecdotal, that public opinion (and maybe legal opinion) is strongly moving in favor of the right of individuals to demand non-beneficial treatment.

MEDIA ATTENTION SURROUNDING END-OF-LIFE CARE

Recent books and research seem to question the circumstances in which the medical community can refuse to provide supposed non-beneficial care, especially in end-of-life cases. One book, *Cheating Death*, by Dr. Sanjay Gupta, questions whether an individual who is declared brain dead is actually dead. Dr. Gupta discusses a few fascinating cases in which a family, despite being told that their loved one was brain dead, refused to "give up", and the patient miraculously recovered. Dr. Gupta questions whether the current tests used to determine brain death are scientifically sound and reliable. As Dr. Gupta is a notable commentator on medical subjects, his book has received much notoriety and many are captured

by the belief that even though a patient has been declared brain dead, there is still hope that the patient can recover. This book, along with other similar publications, continues to highlight the difficulty of determining brain death and provides families with hope that a loved one might recover.

Additionally, a study recently conducted in Belgium questions the medical community's current understanding of patients who are in a persistent vegetative state.⁵ Current medical evidence indicates that patients in a persistent vegetative state have no ability to communicate and no cognitive function. However, a recent study, using MRIs to detect brain activity, identified activity in the areas of the brain associated with "yes" and "no" responses when investigators asked specific questions to patients in a persistent vegetative state. If nothing else, this study shows that, for patients in a persistent vegetative state, the medical community has much to learn and that perhaps current understanding is not as solid as once believed. These books and studies provide families with hope that an end-of-life patient may be able to recover and they make the decision to withdraw support more difficult. In addition, these studies question the deference given to the medical community to refuse to provide care that it feels is medically inappropriate or that would provide no benefit to an individual.

Also, with the recent initiatives to reform our health care system, part of the conversation devolved into discussions about so-called "death panels." This debate, although fraught with misinformation, reflects the vigor with which some individuals and families will fight to preserve their right to make medical decisions without interference from the government or health care providers. Perhaps these discussions will affect, and ultimately limit, the circumstances in which the health care system can refuse to provide treatment.

CONCLUSION

The ethical dilemma of providing medically inappropriate care, especially at the end-of-life, continues to generate heated debate. With medical technology advances enabling people to live longer and allowing physicians to question current medical standards by delving deeper into the human mind and body, disputes will undoubtedly continue between families that demand everything be done and the medical community that feels uncomfortable providing care that may not benefit the patient. Recent legal decisions have not necessarily prohibited the health care system from refusing to provide care, but they have questioned, and perhaps narrowed, the circumstances in which the medical community can refuse to provide care it believes is both ethically and medically inappropriate.

REFERENCES

1. AMA Code of Ethics, Opinion 2.035, Issued June 1994.
2. Texas Advance Directive Act. Chapter 166 of the Texas Health and Safety Code. In essence, after other avenues are exhausted, the Act allows hospitals and physicians to withdraw medical care determined to be futile, if the patient's surrogate decision maker is unable to locate a medical provider willing to continue providing care.
3. *Betancourt v. Trinitas Regional Medical Hospital* (Superior Court of New Jersey), 2009.
4. *Children's National Medical Center v. Brody* (D.C. Superior Court), 2008.
5. Summary of research report obtained from: "Trace of Thought is Found in 'Vegetative' Patient" <http://www.nytimes.com/2010/02/04/health/04brain.html?ref=health>. Last accessed February 5, 2010.

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