

Essay

Autonomy and End of Life Decision Making: Reflections of a Lawyer and a Daughter

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What is the role of autonomy in end of life decision making? As a law professor specializing in this field I thought I knew the answer. As a family member facing end of life decisions of a loved one, I learned first hand of the gulf between law and life.

A Legal Perspective

As a law professor, I spend much of my time educating future lawyers about the law's approach to end of life decision making. This issue basically arises at two different times: (1) at the planning stage, when an individual is healthy and competent and in a position to state his wishes and (2) when a person is in a compromised state, such that he cannot make or express wishes for himself, but health care decisions must be made. Although these situations are vastly different, the operating model is the same. In both situations, the law is concerned with maintaining the autonomy of the individual. The question of how one accommodates the needs of the family is ignored as the family's preference is largely irrelevant within this legal model.¹

In preparing future lawyers who are going to be involved in estate planning, I teach them the importance of advising clients to make their wishes known regarding end of life care. I also teach them about drafting the legal documents that reflect those wishes: the health care proxy and the living will (sometimes these documents are referred to under the generic term "advance directives.") Although these documents operate in different ways, they both attempt to provide an opportunity for the person's wishes to be taken into account in the event that he becomes unable to express his own wishes.

The health care proxy is a document that allows a person to appoint another individual as an agent to make decisions regarding health care if the principal is unable to make such decisions or unable to communicate decisions to health care providers. The theory underlying the health care proxy is that of substituted judgment; the agent's role is to convey the end of life decision that the principal himself would have made if able to do so.² In doing so, the health care proxy

¹ Susan Adler Channick, *The Myth of Autonomy at the End-of-Life: Questioning the Paradigm of Rights*, 44 VILLANOVA L. REV. 577, 581 (1999) ("In death and dying jurisprudence, the centerpiece of rights talk is personal autonomy—the almost unassailable right of an individual to make medical treatment decisions even when such decisions result in the accelerated death of the actor.")

² See RAY D. MADOFF, CORNELIA R. TENNEY & MARTIN A. HALL, PRACTICAL GUIDE TO ESTATE PLANNING 57 (2001).

uses the autonomy model to reflect the patient's wishes and does not provide any mechanism to reflect the perspectives family members—even if a family member is named as agent.³

A living will is the other commonly used document in planning for end of life decision making. Like the health care proxy, the living will strives to provide an opportunity for input by the individual. However, rather than relying on an agent, the living will is a document that provides specific instructions for medical care.⁴ A living will contains instructions directly from the principal to the health care providers. Therefore, in theory, the instructions are effective even if the family members disagree with the decision.

Even from this clear-cut lawyers' perspective, I try to impart to my students awareness of some of the practical limitations of this model. After all, drafting a living will requires imagining situations that, to most people, are simply beyond imagination. To illustrate this problem, I often show my students an episode from the popular television show Seinfeld. In this episode one of the characters, Kramer, having watched a movie about a woman in a coma, decides he needs a living will. Kramer asks his friend Elaine to be his designated agent for health care decisions and together they consult an attorney to draft the appropriate documents. To prepare the living will, the attorney goes through a variety of scenarios and asks Kramer what type of medical care he would like for each. The following colloquy captures the flavor of the meeting:

Attorney: Situation #4: You're breathing on your own, you are conscious but with no musculature function...

Kramer: Well, would I be able to communicate?

Attorney: I don't see how.

Elaine: I don't like the sound of this one

Kramer: Aaah, let's pull the cord

Elaine: Yank it like you're starting a lawnmower.

Even if this is written broadly for the sake of humor, as is often the case, the humor contains a good deal of truth. Although people regularly prepare living wills that state their wishes in the event of various circumstances, it is very difficult to imagine those situations and to perfectly predict how one is going to feel. One of the limitations of the living will is that it presumes that people, when they are young and healthy, are going to be able to accurately assess how they would feel in the face of serious and debilitating illness. And the truth is...we don't really know whether people do in fact feel the way they imagine they will in such situations. Indeed, the bulk of the evidence points in the other direction. It is not uncommon for people to say things like: "if I were paralyzed (or blind or suffered a stroke or any number of other

³ See Channick *supra* note 1 at 637-638 (“[D]espite the relationship of patients with their families, the culture of death and dying has conspired to exclude the family from one of life’s most intimate moments”).

⁴ See, Madoff, Tenney and Hall, *supra* note 2. at 56.

debilitating conditions that humans face), I would not want to go on living.” But yet, when people actually face these situations, their attitude is typically very different. The will to live is so strong, that although they may at first be discouraged about their situation, most people continue to find meaning in their lives, even if they didn’t think they could.

That is how the legal world addresses advance decision making, but what about the situation where there is no explicit advanced directive, but a decision about medical intervention must be made? The legal model again focuses on the individual. If she is competent to make the decision, then she should do so. This makes perfect sense because medical intervention in the absence of consent is a battery, an unauthorized assault on someone’s body. Therefore, it is natural to first look for consent. Yet, understanding consent in the context of “live” end of life decision making can be far more complicated than it initially appears.

One of the most well known cases to address this situation involved a young woman, Karen Ann Quinlan, who collapsed at a party after swallowing alcohol and tranquilizers. Doctors saved her life, but she suffered brain damage and lapsed into a persistent vegetative state. Her family sought to remove her from life support machinery, but the doctors objected. The question eventually went before the New Jersey Supreme Court, which recognized the right of a person in a persistent vegetative state to be taken off of life support machinery if that is her wish. As the court stated:

We have no doubt, in these unhappy circumstances, that if Karen were herself miraculously lucid for an interval (not altering the existing prognosis or the condition to which she would soon return), and perceptive of her irreversible condition, she could effectively decide upon the discontinuance of the life-support apparatus, even if it meant the prospect of natural death.⁵

Although this decision makes perfect sense in the abstract, if one could imagine such a situation actually happening, some of the difficulties of this model become readily apparent. Let’s imagine that Karen Ann Quinlan were to miraculously become able to express her wishes and she wakes and says “Oh my G-d, this is awful, pull the plug!” There would still be questions as to whether this reflected her well thought-out decision or whether the comment reflected initial depression at her circumstances. Do you treat the depression? How do you know when you have a decision that truly reflects that person’s wishes? It is notable that even the fantasy of sudden lucidity still raises problems for end of life decision making.

And, of course, most people don’t have such clear moments of lucidity. Far more common is the situation where patients are not able to express their wishes and indeed may not even be competent to form their decision, and you have the family and medical personnel and decisions that must be made. The real life situations are significantly more complicated than the legal construct imagines.

⁵ In re Quinlan, 70 N.J. 10 (1976). For a discussion of the case law in this area *see*, Charles H. Baron, 17 FAM. L. Q. 1 (1983).

A Daughter's Perspective

This was all brought home to me in a very personal way when my father took sick several years ago and we faced these difficult decisions.

My father was a doctor, a cardio-thoracic surgeon who was well acquainted with the problems that people face at the end of life. One thing that he knew was that he did not want anything to do with it. So he did what he could to make his wishes known. Massachusetts is one of the few states that does not explicitly recognize living wills. Nonetheless, my father carefully wrote a note that he kept in his desk drawer that said: "If anything should happen to me, I do not want any extraordinary measures taken." So, one thing we had in determining his wishes was the gold standard document, a statement written when he was healthy that explicitly stated his wishes. My father was not taking any chances, so in addition to this note, he also designated a health care proxy. Here too, his wishes came through loud and clear. A spouse is a common choice for people in naming a health care proxy, and my mother, his wife of almost 50 years, might have seemed a natural choice. Nonetheless, my father, most likely mindful of my mother's soft heart and her notoriously anti-death stance, eschewed the obvious choice in favor of my brother—another surgeon who was capable of making the hard decisions. Although this decision on its own was worth a thousand words, my father also added a few of his own. In a conversation with my brother, my father said: "I have named you my health care proxy and I don't want any monkey business!" My brother knew just what he meant.

So one thing we knew when facing these decisions was what my father's wishes were—at least his wishes when he was healthy. But, by the time we were facing these very difficult decisions, many things had changed in my father's life.

My father was an extremely active and vibrant person through his early 80's. At the age of 83 he was still practicing cardio-thoracic surgery with a roster of over 50 patients (the fact that so many people would trust their lives to an octogenarian surgeon was a testament to his caring nature as well as his knowledge and skill). In addition, he was taking courses at Harvard Extension School and was in the public library researching Spinoza on the day that he suffered a massive stroke.

Strokes can be mild or they can wreak havoc. My father was one of the unlucky ones. Like many victims, my father's stroke left him essentially paralyzed on his right side-- unable to walk or use his right hand. More cruelly, it robbed him of his ability to speak. He could start a sentence, but couldn't finish it, and as much as we tried to understand him, the ultimate effect was to isolate him from friends and family. The stroke caused other, less common, afflictions as well. My father had been a lifetime lover of jazz music, but the stroke affected his ability to understand the notes. It just sounded like noise to him. He was even robbed of the basic pleasures of eating because he lost his ability to taste most foods. His condition was reminiscent of the trials of Job.

My father's life continued this way for the next three years. During that time, although he was often profoundly depressed, at other times he seemed to make do. He enjoyed going for

rides with my mother, watching his grandchildren, and even the occasional ice-cream cone. It seemed like a new normal had been established.

Of course, all things change and even new normals eventually become things of the past. About three years after his initial stroke, my father began suffering a variety of life threatening ailments. At one point, he developed an infection and his temperature dropped to 86 degrees Fahrenheit. At another point he started aspirating food and developed a form of chronic pneumonia. And at each time, we needed to make decisions about what course of action to take. It was at this time that I became most intimately aware of the difficulty of these decisions and the limited assistance provided by the legal view of the world.

We had my father's statement of his wishes, but were they still applicable? Although they might have provided guidance for his views when he was healthy, were those still his views? Of course, if we didn't follow those wishes, how should we decide? Here again, there were a variety of views. My mother and sister were against death at all costs. As my mother said, "this is his only life, who are we to take that away from him?" My brother and older sister looked at the situation from an objective standpoint—was this kind of life really worth living? I wanted to use the autonomy model, but had a hard time applying it to the situation. On one hand my father had clearly expressed his wishes years before, on the other hand after having his stroke he continued to take his medicine and take other life affirming actions. All of this suggests that even when everything happens just as it is supposed to in our legal system, this does not mean that the answers are clear.

Perhaps most surprising was the approach of medical professionals to these health care decisions. Although they were aware of my father's health care proxy naming my brother as his agent for the the purposes of making health care decisions, and my father's letter expressing his wishes to avoid extraordinary measures, they nonetheless worked with the entire family to come to a group decision about the appropriate treatments. They used these legal documents, not as answers in and of themselves, but rather as tools to move the family towards consensus about what was in my father's best interest.

In the end, my father had one of those "moments of lucidity" that allowed the autonomy model to work. It had become clear, that if my father's life were to continue, he would need to have a feeding tube. We agonized over the decision and talked for hours on end about what to do. Eventually, I spoke with my father and told him about the doctor's suggested course of action. "No!, No!, No!, No!" he told me, making his wishes known in no uncertain terms. I said, "you know, if they don't put in a feeding tube, you will die." He mustered all of his strength to say, "I know. I don't care." And when I told him I understood what he wanted he turned to me and said "I'm sorry."

My father died at home two weeks later. Although I will always miss him, I feel fortunate in the comfort of feeling we made the right decision. For those families that are not so fortunate as to have a clear statement of their loved one's current wishes, the experience with my father has caused me to question, not necessarily the appropriateness of the autonomy model, but the helpfulness of the model. As much as one might want to take into account the true wishes of the patient, in many situations the patient's true wish is probably anybody's guess.

Understanding the Gulf

This essay has discussed the vast gulf between the legal perspective and the perspective of a family member in facing end of life decisions. The former uses a strict autonomy model, the latter, recognizes that the issue is far more complex. How can we understand this divide?

Legal scholars have long recognized that there is a distinction between law-on-the-books and law-in-action.⁶ In action, law-on-the-books often acts as only one of many factors in decision-making. A posted speed limit is interpreted by many drivers as a guide rather than a hard and fast rule of driving. The allocation of liability between persons from law-on-the-books is taken as a factor among others (e.g., whether the plaintiff has the resources to take her case to court or whether the defendant has sufficient assets to pay a liability) to be considered by parties in negotiating a settlement to a dispute. Similarly, in end of life decision making, the law-on-the-books model of patient autonomy acts as a factor, among others, in the messy, complicated law-in-action of end of life decision making.

When making decisions about end of life care, medical professionals work with families and loved ones to reach a consensus. In guiding families, the directions of the patient as expressed in the living will or choice of health care proxy are offered up as factors to be considered in the decision. At first glance, this approach may seem to be disregarding of The Law (capital “T,” capital “L”). However rather than being disregarding, this approach instead reflects a more nuanced understanding of law and what it does and does not do. Law is not a decision-making machine to be applied in all circumstances. Indeed, although law-on-the-books may provide *an* answer, it does not necessarily provide the *best* answer. Medical professionals operating on the front lines are correct to understand this approach and incorporate it into their actions. In addition, law on the books serves another important function as well. It serves as a final arbiter for hard cases where consensus cannot be reached. Although this system may have its flaws, like democracy it may just have fewer flaws than the alternatives.

⁶ This terminology was coined by Roscoe Pound in Roscoe Pound, *Law in Books and Law in Action*, 44 AM. L. REV. 12 (1910).