Advance Directives are Often Not Honored
by Michael Cook

Advance directives give peace of mind to patients and their loved ones because they can be sure that their health care wishes will be followed even if they are not able to communicate.

At least that's the theory.

In practice, the situation is different, according to Susan P. Shapiro, a sociologist with the American Bar Association. After observing a thousand interviews of doctors with families in two intensive care units, she found that what happens is far more complicated. She presented some of her results at a meeting of the ABA last year (thanks to the Medical Futility Blog for the tip).

Only about 36% of patients or their spokespersons claimed to have an advance directive. And in only about 10% of cases was the directive read. Sometimes it could not be found. In about one-third of patients with an advance directive, neither the doctor nor the families mentioned it.

In about 25% of cases, the advance directive worked according to plan, giving peace of mind and a clear plan of action. But in 45% of cases, "there was no discernible evidence that the directive made any difference," she said. It was either never mentioned, "or if somebody tried to talk about it, it fell on deaf ears; the family didn't want to have anything to say about it." Sometimes the preferences were "simply flouted or ignored or disregarded".

Sometimes patients changed their minds about the treatment they wanted, but they did not change the advance directive or tell their families. "And so what is written in stone are wishes that no longer apply to the patient."

After her research, her advice was to write down as little as possible. "Decision-making in a hospital setting is not easily subject to control -- either legally or otherwise. To believe that it is provides a false sense of security and probably increases the likelihood that a client or a family member or your own wishes will be undermined. The impulse should be to have less law, less formality, less specificity."