

Futile Medical Care and the Limits of Law

Bill Colby

In the spring of 2007, a 19-month-old baby named Emilio Gonzales died in Austin, Texas. He lived the last six months of his life in the Pediatric Intensive Care Unit (or PICU) at Austin Children's Hospital, suffering from Leigh's disease, a rare and fatal genetic disorder. Emilio's doctors believed that he was blind, mute, and unaware of the world except for pain. Earlier this spring they told his mother that they wanted to turn off the mechanical respirator that breathed for Emilio. Ms. Gonzales believed that her son knew when she was there, and would not consent.

The hospital gave her official notice of their plan to proceed nonetheless, under a 1999 Texas law that gives hospitals the authority to discontinue medical treatment against the wishes of a family if doctors and the hospital ethics committee believe the treatment futile. Ms. Gonzales went to court and blocked that action and the judge set a date for the trial, but Emilio died eleven days before that joyless, tear-filled trial was to begin, his respirator still in place.

The issues raised in the Gonzales case are neither abstract, nor rare. Each day in the U.S. about 7,000 people die. Most of these deaths come in institutions, and most as a result of some decision – respirators removed, dialysis stopped, antibiotics refused. The majority are elderly – 3,800 over age 75. But nearly 100 babies die each day, too. Daily, families and doctors of the young and old alike confront the profound questions that rapidly-advancing medical technology have brought us: What's the purpose of medical treatment? When do we use it, and when do we stop?

The answers are seldom obvious, and as seen in the Gonzales case, the ability of the law to definitively answer such questions is limited. The law can provide structure, process, and ultimately judgment. But it seldom can provide satisfying moral resolution.

In fact, consider just how odd the laws involved in end-of-life cases are. In 1976 California passed the first state living will law. The law gave Californians the method to write down medical treatments they might want to reject if they could no longer speak. Most states now have such laws. The 1999 Texas futility law at the center of the Gonzales case accomplishes the opposite result, allowing doctors to say no to a treatment that a patient or his family demand.

But most doctors I know have dedicated their lives to helping others, and they're good at it. Most people I know want that help. Why should we need the Texas futility law for doctors to overrule families? Or living will laws for families to overrule doctors, when the main goal of doctor, family, and patient is identical? What strange laws.

And what new laws – 30 years ago none of these laws existed, and the phrase "let nature take its course" still meant something. No longer. That's the complicated world of

modern medical technology. Of course, we all know stories of cure, triumph and recovery. As a culture we believe in the abilities of doctors to fix nearly any problem, and often they can. When they cannot, though, we face hard choices.

On November 1, 1990, after almost four years of highly-contentious court fights with the state of Missouri all the way to the U.S. Supreme Court, my client and friend Joe Cruzan received the final court order granting the relief he sought, to remove the feeding tube from his permanently unconscious daughter. Joe said, “Well, if that’s winning, we won.” I will not forget his face – a man in his fifties, he looked eighty, with the energy sucked out of him.

Emilio Gonzales spared his mother and doctors that long journey through the court system. However the courts might have ruled, it’s unlikely that either Ms. Gonzales or the doctors would have felt any more victorious in the end than they did last Saturday night, when Emilio died. Everyone lost when genetic fate consigned a baby to a short painful life in the PICU.

The democratic process is cumbersome, and inefficient by design. When decisions are easy in society, we make them and move on. When they’re not, and the courts get involved, the process is often excruciating for those caught in the middle, like the Cruzans, or the family of Terri Schiavo, or Catarina Gonzales. The rest of us in the democracy typically benefit, however, because these tragic stories cause us to stop and talk for a bit about topics we don’t easily discuss—like serious illness and dying.

So take a minute and talk with someone today – thoughtfully, compassionately – about baby Emilio and the questions that his mother and doctors faced. Understand that the goal of the talk with those you love is guidance and understanding, not “right answers.” There perhaps are no right answers, but the questions about end-of-life treatment are ones all of us eventually will face.

Bill Colby is a former Senior Fellow of the National Hospice and Palliative Care Organization and the author of *Unplugged: Reclaiming Our Right to Die in America*. For more information and free planning documents, go to www.CaringInfo.org or call 1-800-658-8898.