Trying to Practice What I Preached: Helping My Parents at the End of Their Lives

Steven A. Schroeder, MD, University of California, San Francisco (UCSF)*

May 2012

Once again, the challenge of how to constrain rising health care expenditures has caught the public interest, stimulated by concerns over rising federal debt and limited ability to generate tax revenues. I recently chronicled my unsuccessful efforts at stimulating medical cost containment from both academic and foundation positions (1971–2002) in the April 23, 2011 issue of the Archives of Internal Medicine. What I did not relate was how hard it was to put into practice for my own family the principles I had been espousing all those years.

Mom and Dad moved to El Cerrito, California, in 1954, into a small house north of Berkeley with a splendid view of the Golden Gate Bridge. Around age 80, Mom slipped into the early phases of Alzheimer’s dementia. Dad made the decision to keep her home, where she remained until her death at age 91. She had home health aides, and was comfortable, although it was painful to watch her previously keen intelligence fade month by month. Before she became ill, Mom and Dad had asked me how to prevent falling into the patterns of aggressive care, like cancer chemotherapy for advanced disease, that had befallen several of their friends. “Easy,” I replied, “your physicians were trained at the UCSF program that I headed, and they have lots of good common sense.” Even so, there were problems. Mom’s primary care physician was evaluated on criteria that included percentages of patients receiving Pap smears and mammograms, so Mom got those every year even though she was not a surgical candidate. And then there was the painful Mohs procedure for a facial basal cell carcinoma that was performed to prevent subsequent spread and scarring; that occurred at a time when she had stopped talking and had to be fed. I found it difficult, during my cross-country visits, to persuade the devoted attendants and my father to forgo those interventions. I also felt uncomfortable. Was I being callous by denying my own mother medical care that experts thought she needed? Still, Mom had what we might consider a “good death” at home, under hospice care, and with small doses of morphine the last few days.

When we moved back to the Bay Area the year after Mom died, I helped to manage Dad’s care more directly. He was adamant about not going to a nursing home, and was quite independent until age 97. But his intermittent atrial fibrillation met guideline standards for anticoagulation, and I had to persuade his very good general internist that Dad’s habit of climbing on ladders and sometimes falling during outdoor repair work did not make him a good candidate for...
the anticoagulant Coumadin.

Ultimately, even this stalwart patriarch weakened, and we recruited a set of devoted home care attendants to come in and help. Dad’s smoking habit, which he fortunately quit in his 50s, had left him with a chronic cough that alarmed the attendants. There were frequent calls to 911, which resulted in a cascade of trips to the local emergency room and multiple tests and X-rays. I made up a sign that asked that I be contacted before calling 911, and all the attendants agreed that was a reasonable plan. But one night an attendant became alarmed, called the wrong number, and when she heard a message that the phone was out of service she panicked and called 911. Dad was transported to a different hospital from the one that he usually frequented. I was called the next morning and told that he had pneumonia and needed hospitalization. I promptly drove over, reviewed the chest X-ray with the emergency physician, and offered that the X-ray findings might be chronic rather than acute (the old films were at his usual hospital, so they couldn’t be compared). We agreed that he could probably come home, and Dad was delighted. A year and a half later, he died quietly at home, shortly after his 99th birthday, again assisted at the end by hospice. The probable diagnosis was primary frailty.

What I just described is a good outcome. Both my parents got what they wanted—a long life, no hospitalizations, and the opportunity to die at home. But in spite of the fact that they had a physician son, personal primary care physicians who believed in restraint, and devoted caregivers, it still required active management to keep them off the treadmill of aggressive medical interventions. In a culture where withholding care is seen as rationing or worse, and where sins of medical omission are scrutinized more closely than sins of medical commission, restraining medical expenditures will not be easy. At the very least, I look forward to a time when these issues can be discussed in public without finger-pointing or acrimony. That time is not yet here.

*Steven Schroeder is Professor at the University of California, San Francisco, Director of the Smoking Cessation Leadership Center, and former CEO of the Robert Wood Johnson Foundation.*