people choosing to pay the penalty instead of purchasing insurance do not collect a tax credit — though some unknown proportion of them (those with incomes exceeding 400% of the federal poverty level) would not have been eligible for one anyway.

Although the ACA’s expansion of coverage has substantially reduced the number of uninsured Americans, the sustainability of the new health insurance marketplaces depends on the affordability of insurance for both individual consumers and the government. That affordability, in turn, depends on the policy decisions that determine the structure of the individual marketplaces. It’s estimated that at least 20 million Americans who were eligible to purchase insurance on the exchanges in 2015 did not do so. Moreover, with expiration of the reinsurance program in 2016, premiums will almost certainly increase in 2017, which could discourage some people from becoming insured and others from remaining so. Thus, continued efforts to increase and maintain participation are needed — such as greater outreach to people on the entire spectrum of the risk pool, more publicity about and enforcement of the mandate to obtain health insurance, and sparse use of exemptions from the mandate’s penalties. The expiration of the grace period for noncompliant plans in December 2017 should also help expand the risk pool.

The effect of allowing ACA-noncompliant plans emphasizes the importance of ensuring near-universal participation in the risk pool and provides a cautionary tale about the unintended consequences of altering a single policy within the interwoven set of ACA reforms.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

A Modern Ars Moriendi

Katherine C. McKenzie, M.D.

My father the rancher was stoic and taciturn. His cowboy hat and boots were no affectation: the boots protected him from snakebites; the hat shaded his face from the strong sun of the Colorado plains. He loved everything about his 3300-acre ranch — from the stark, flat, expansive landscape to the house whose dining table hosted countless family meals and whose living room welcomed an untold number of friends. Until fairly recently, he had tended his land and cattle with vigor and joy.

One Monday afternoon in the spring of 2015, my sister telephoned to say that Dad’s neighbor Rocky had just contacted her. “Dad is alive, but he can’t speak or move his right side. Rocky found him lying on the kitchen floor. The ambulance is on its way.”

Decisions about his health care loomed, and during the next 4 days I shifted among the roles of daughter, health care proxy, and physician. It was disorienting, difficult . . . and transformative. After 20 years of taking care of patients as an internist, I was now plying my trade with my closest family member. I didn’t want him to suffer. I wanted him to have a good death — something akin to the ars moriendi.

Latin for “art of dying,” the ars moriendi is a body of literature that originated in Europe during the 15th century, on the heels of the bubonic plague. Its aim was to provide a practical and spiritual framework for the prepara-
tion for death. It outlined prayers and protocols for the dying and for their communities. It emphasized the acknowledgment of human finitude. My father had never heard of the _ars moriendi_, but I was certain that it was what he would have wanted. In his living will and in past family discussions, Dad had been clear that he wanted no mechanical ventilation, no resuscitation, and no feeding tubes. And he wanted to die at the ranch, if possible.

Dad had become acutely ill at home a year earlier, but he'd refused to leave his house or seek care. He recovered from that illness, but it was now clear that he would accept medical care for symptom relief only. He didn't want treatment for a life-threatening illness. Physical decline due to arthritis and gout was evident, as his feet swelled and he could no longer wear his boots — instead, he wore sneakers for the last year of his life. The image of Bob McKenzie without cowboy boots was disconcerting.

When I arrived at the hospital 14 hours after my sister's call, Dad was unresponsive. I held his hand, but he didn't squeeze mine in return. His eyes remained closed. His doctor said he'd had a large stroke, he would require 24-hour care for the foreseeable future, and it was unlikely that he would ever return to his prior level of independence. Hospitals, medical care, interventions: my father would have had none of these had he been conscious. I shouldered my burden as health care proxy and began the task of aggressively withholding all but comfort care for his serious albeit potentially treatable illness.

We arranged for an ambulance to transport him back to the ranch as soon as possible. “We're leaving the hospital, Dad. We're taking you to the ranch now.”

The spring air was warm when the EMTs brought Dad into the house. It smelled of leather, dust, and chewing tobacco. His breathing became more regular, and his agitation diminished; I believe he knew he was home. Removing him from the hospital most likely hastened his death. But the days that remained were rich — and in accord with his oft-stated wishes.

Voices soon filled the house; friends and family streamed in and out of his bedroom and paid their respects with quiet words and gestures, but with humor and laughter, too. The parish priest, Father Herman, administered the last rites, and a bedside vigil of contemplation and comfort unfolded for 3 days.

In her book _Dying in the Twenty-First Century_, Lydia Dugdale asks whether we can revive the _ars moriendi_, despite our highly medicalized approach to dying. Looking at my dad, in his home, unencumbered by medical technology, I thought we had come pretty close. Here he was, embraced at home by the people who cared for him most. No medical teams on daily rounds, no machines to keep him alive. Just the smell of the plains, the comfort of his own bed, the voices of his loved ones.

Sometimes I wondered whether I'd made the right decision. Modern medicine has made it possible for patients to live after a stroke, although often with significantly compromised function. On his second day home, Dad began to cough and became febrile, and I suspected that pneumonia had developed. As a physician, I knew an antibiotic would be an appropriate and relatively low-risk intervention, but we withheld that treatment along with the others. He received medication to alleviate his discomfort, and that was all. But despite his clearly stated desires, I knew well what was theoretically available to keep him alive.

Near the end of our vigil, my sisters and nieces and I were emotionally weary. As we sat with a neighbor in the living room adjacent to Dad's bedroom, the neighbor inquired about the piano in the living room and mentioned that she played. “Could you play a piece for us?” we asked. Soon, plaintive, melancholy music surrounded us, soothing our sadness as we prepared to say goodbye to our father.

His condition continued to deteriorate, and on Thursday morning, my sister told him, “Dad, it's a beautiful morning. It's okay to go now.” Shortly thereafter, his breathing shifted and slowed, and then stopped. We held his hands and one another's, feeling deep sorrow and a reverence for death.

**Dad had been clear that he wanted no mechanical ventilation, no resuscitation, and no feeding tubes. And he wanted to die at the ranch, if possible.**
In the year that has passed, I have been thankful to Dad for his foresight in preparing himself and his family for the kind of death he wanted. It was a challenge to resist the medical treatment I knew so well. But in honoring his wishes, we shifted our focus from life-prolonging technology to life-enriching community. And we managed to apply 15th-century principles to achieve a timeless outcome: a good death.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

From the Yale School of Medicine, New Haven, CT.


DOI: 10.1056/NEJMp1601820
Copyright © 2016 Massachusetts Medical Society.