In the fall of 2013, our 86-year-old dad, Robert Drye, a heart failure patient, mentioned to us that his cardiologist was going to repair his cardiac device. Dad has an implanted dual-chamber pacemaker and defibrillator (pacemaker/implantable cardioverter-defibrillator [ICD]) that will pace his heartbeat if it beats too slowly and provide a shock if he develops a life-threatening irregular rhythm. His cardiologist could not get a recording off the device, presumably because of a failure of the wire that connects it to the heart’s rhythm system. He referred Dad to his electrophysiologist, his cardiologist specializing in heart rhythm problems. The specialist informed Dad that the failing lead might cause the pacemaker/ICD to fire inappropriately and proposed performing a procedure to disable the lead and place a working one. He told Dad he would have to stay in the hospital overnight. He did not mention any risks of the procedure other than infection.

We were ambivalent about the ICD procedure. In fact, it is fair to say we were biased against it; one of us helped develop a national ICD complications quality measure and the other is a palliative care doctor. We were both well aware of the risks but not sure of the benefit. We decided we should share our reservations with Dad and make sure that having the device repaired was the right decision for him.

Our dad was living at home but seemed to be increasingly frail. Seven years before, Dad had a cardiac arrest. A sudden block in the blood flow to his heart damaged the heart muscle and caused a usually fatal heart arrhythmia called ventricular fibrillation. Paramedics arrived within minutes and successfully resuscitated him against the odds. His pacemaker/ICD was implanted emergently, and he later underwent stenting of his blocked coronary artery. His recovery was spectacular, given the circumstances, and he returned home with a relatively good quality of life and his mental abilities fully intact. However, he did have mild fatigue from well-compensated heart failure and a slightly less steady gait. He could walk slowly for a mile but sometimes experienced leg weakness leading to falls. His worst resulted in a fractured sacrum and a small bleed in his head contributed to by his blood thinner medications.

Although its initial placement was clearly indicated, the device’s benefit was not clear. It had never fired. Dad had not been pacemaker-dependent and had no life-threatening arrhythmias. Our concern was that the procedure presented real risks that might make Dad worse off. The known complications of cardiac device placement include not only infection but bleeding and pneumothorax (an air leak into the space between the lung and the chest wall, collapsing the lung). In addition, time spent in the hospital posed its own risks, including infection and deconditioning.

So what was his point of view? When advised to have a new lead placed, Dad had a good understanding of the procedure. He graduated from New York University School of Medicine in the 1950s, practiced as a psychiatrist, and is better versed than most in medical nuances. Still, we wanted to make sure he had fully weighed the trade-offs, so one of us (Barbara) called him on the phone from out of state.

She asked, “What complications were you told about?”

Dad replied, “The cardiologist said I had to be careful about my arm for a few days. They plan to watch me overnight.”

Barbara asked, “Was the option of not doing the procedure discussed?”

“No.” He said the cardiologist had told him the ICD would not be reliable without repairing the lead, so he had not hesitated.

She probed further, “What do you think about having the procedure, knowing that your ICD has never gone off?”

Dad replied firmly, “I want a working ICD. I saw the procedure as a minor one that provided insurance against a potentially fatal event.

He had the lead placed, experienced a pneumothorax, and spent 4 extra days in the hospital. A catheter connected to a suction device was placed in his chest wall to draw the trapped air out and allow his lungs to expand, so he could not move around much. The extra days in the hospital with little movement were harmful to Dad. Shortly after discharge, he experienced another fall. Since then, his pace wire is reading perfectly, but he has had several more episodes of leg weakness, more falls, and a fainting episode that landed him back in the hospital. We worry that his health is at a new, lower baseline.

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Arguably, Dad’s decision was consistent with his preferences and he was just unlucky. When we asked him about it afterward, he was clear that hindsight was not going to make him rue his original decision. He said he did not see himself as imminently dying and had hoped to maintain his current status. So, it is doubtful that a fuller airing of the issues would have shifted his preference away from intervention and avoided needless suffering. Our perspective was not his perspective.

After talking to our dad, we felt assured that he had made the right decision for him but distressed that other patients may not have that opportunity. We suspect that patients with cardiac devices have diverse needs and views encompassing his and our perspectives. Given the broad range of patients’ potential preferences, Dad’s doctors’ preprocedure conversations with him were woefully inadequate. They failed to share at least 2 critical issues for Dad’s consideration.

First, most complications are treatable, if uncomfortable, but as is now well documented in the literature the extra days in the hospital associated with their treatment can contribute to significant decline. How can doctors best incorporate this new knowledge when they discuss procedures and their potential complications with patients? If physicians fail to share the inherent risks of hospitalizations, they will be understating the risk involved in procedures requiring hospital stays, skewing patients’ decisions in favor of intervention.

Second, turning off the device was another and possibly, for many patients, better option than incurring procedure-related risk, yet Dad’s doctors never presented this alternative. He does not fall neatly into any group where this alternative has been routinely considered. He is not terminally ill. He does not have end-stage congestive heart failure. Yet, the lead failure presented an opportunity—and, we think, an imperative—to explore Dad’s point of view on the importance of the device versus the risks of fixing it.

What do cardiologists discuss with their patients regarding these devices and their benefits in advanced age? Ideally, Dad’s cardiologists would have at least presented the option of turning off the ICD to test whether that fit with Dad’s advanced directive and goals of care. There is little guidance on this topic. A consensus statement written by experts focuses only on deactivating ICDs in patients with known terminal illness in their last few days of life, but many patients would benefit from earlier conversations, particularly if their goals of care are shifting. In a recent eloquent commentary in JAMA Internal Medicine, Drs Matlock and Mandrola call on all caring clinicians managing patients with ICDs—from primary care physicians to electrophysiologists—to periodically initiate this discussion. There may be people in advanced age who want to consider how having their device on or off affects the likelihood of a quick and painless death (from a fatal heart arrhythmia) over a more symptom-laden, gradual demise (from end-stage heart failure). Implications for the patient’s quality of death may matter as much to patients as how the device could affect the timing of death.

As physicians, we can be continually surprised by what people may be thinking about their own healthcare preferences. We will frequently be wrong in our assumptions and certainly will never know unless we ask.

Addendum

Our father died unexpectedly at home in April 2014.

References


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Older Patients With Cardiac Devices: The Need for Better Patient–Doctor Conversations
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