Implantable cardioverter-defibrillators (ICDs) are well documented to save lives in many patient groups for primary and secondary prevention; however, although the ICD is highly effective at preventing sudden death, everyone will die eventually, whether of underlying heart disease or other terminal illness such as malignancy. As the population of patients living with ICDs expanded, case reports began appearing in the palliative care literature such as, “Death and defibrillation: a shocking experience” and “And it can go on and on and on.” ICD shocks are painful, described by patients as “a punch in the chest,” “being kicked by a mule,” and “putting a finger in a light socket,” and it is not surprising that receiving shocks at the end of life would be a distressing experience for the dying patient as well as his or her family. How often this actually happened was first described by our group in 2004. Interviewing family members of deceased patients from our practice, we found that 20% were reported to have received shocks in the last weeks, days, or hours of their lives. More recently, Sherazi et al reviewed charts of 98 patients receiving ICDs in the Multicenter Automatic Defibrillator Implantation Trial II (MADIT-II) who later died, finding that only 15% had had their ICDs deactivated, many after receiving shocks in the last week of life. The true frequency of ICD shocks in dying patients, however, was likely underestimated by both of these studies, because neither family nor healthcare providers may have been aware of all shocks received, and in many cases, the only individuals who could have provided the accurate answer may have carried it with them to the grave.

The study by Kinch Westerdahl et al in this issue of Circulation provides a definitive answer to this question, reaching beyond the grave to perform postmortem device interrogation in addition to chart review in a series of 130 patients who died between 2003 and 2010. Among these, 35% had ventricular arrhythmias in the last hour before death, and 31% received a shock in their last 24 hours, including many with arrhythmia storms, some receiving >10 shocks in their final hours. Patients may not have been able to describe these to family or healthcare providers, yet it is likely that close to a third of ICD patients may still have experienced pain as they were dying. Data collection was extensive, with multiple national databases and chart review used to determine the cause of death.

A second important contribution of the present study is the finding that among the 65 patients with a do-not-resuscitate order (52% of the group), 42 (65% of these) had the device programmed “on” at 24 hours preceding death, and 33 devices (51%) were still programmed “on” 1 hour before death. It is possible that the patients purposefully chose to leave therapy active. Studies of patient preferences regarding ICD deactivation at end of life have shown mixed results. Several written surveys of ICD patients regarding preferences for ICD deactivation in hypothetical situations have found that patients may not want deactivation even in the setting of constant dyspnea or frequent shocks. In the only series of patients actually facing the decision in whom the option of deactivation was discussed (6 patients with terminal malignancies, all with a history of treated ventricular arrhythmias), none chose to turn off shocking therapies. However, we found in a recent interview study, again a survey of hypothetical situations, that when ICD deactivation was put in the context of health outcomes such as functional and cognitive disability that are known to influence decision making, most people would at least hypothetically choose deactivation in some situations. It is also important to note that choosing to leave a device on while choosing to forego external resuscitation is not always inconsistent with a patient’s goals of care. For example, for a patient whose quality of life is currently acceptable but who would be unlikely to return to that quality of life after an extensive stay in intensive care after a resuscitated arrest, it may be consistent with his or her goals to leave the device on while choosing not to be resuscitated.

It is far more likely, however, that most of these patients and their families did not realize that deactivation was an option. In our 2004 study, just 27% of patients and families had discussed deactivation at any time preceding death, and this number was only somewhat higher, 45%, among those with do-not-resuscitate orders. In the instances in which that conversation had taken place, most often it was initiated by the patient or family themselves, rather than a healthcare provider. Among physicians caring for patients with heart failure, most report that they do not regularly discuss deactivation with their patients. In a 2008 survey of healthcare providers by Mueller et al, close to half reported they would not be comfortable personally deactivating an ICD. In a more recent qualitative

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study of cardiologists, electrophysiologists, and geriatrians, many physicians reported feeling uneasy discussing deactivation and cited lack of time, lack of long-term rapport with patients as follow-up visits decreased, and a general discomfort discussing withdrawal of care as barriers to bringing up this option with patients.\footnote{13}

The present study by Kinch Westerdahl et al\textsuperscript{a} emphasizes the importance of proactive communication between healthcare providers, patients, and families to prevent painful shocks at end of life. Recent consensus statements by professional societies for heart rhythm providers in both the United States\textsuperscript{14} and Europe\textsuperscript{15} have described the ethical and legal underpinnings of device deactivation, as well as logistic considerations, and have urged physicians and other healthcare providers to take a proactive role in discussion of this option with patients. It is too soon to say whether these consensus statements will achieve their goals of improving the frequency of conversations between healthcare providers and patients and families, because the current series ended in the year in which those documents were published (2010). This series, which shows the incidence of shocks at end of life to be even higher than reported previously, highlights the importance of physicians and other healthcare providers taking a proactive role in discussing the option of deactivation. Other system-based approaches, such as including device deactivation on do-not-resuscitate forms and including the presence of a device and wishes for deactivation on intake forms for nursing facilities and hospices, may also help reduce the incidence of painful shocks as patients are dying, which is documented definitively in the present study.

Another result of the present study that is deserving of comment is the finding of 4 “system-related deaths” (3\%), 3 caused by undersensing of ventricular fibrillation and 1 by loss of capture in a pacemaker-dependent patient. Although lead and generator malfunction is not uncommon, deaths attributable to these malfunctions have not been reported to be frequent. One series of postmortem interrogations in 22 sudden deaths did not suggest any to be caused by system malfunction.\textsuperscript{5} Similarly, in a series of 317 deaths, including 68 sudden deaths whose mechanism could be determined, although some of the patients died of shock failure or incessant-recurrent ventricular arrhythmias, no system malfunctions were reported.\textsuperscript{17} Whether the deaths reported in the present series were truly system related is difficult to determine.

Undersensing can result from 3 broad types of perturbations: Physical lead or generator malfunction, programming issues, or extrinsic influences on the signal by drugs or metabolic changes. Sensing algorithms that adjust dynamic range issues, or extrinsic influences on the signal by drugs or metabolic changes is difficult to determine. Whether the deaths reported in the present series were truly system related is difficult to determine.

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Implantable Cardioverter-Defibrillator Shocks in Dying Patients: Disturbing Data From Beyond the Grave
Rachel Lampert

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