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BRIEF ANSWERS TO SPECIFIC CLINICAL QUESTIONS

Q: Can patients opt to turn off implantable cardioverter-defibrillators near the end of life?

A: Yes. Although implantable cardioverter-defibrillators (ICDs) prevent sudden cardiac death in patients with advanced heart failure, their benefit in terminally ill patients is small.[1] Furthermore, the shocks they deliver at the end of life can cause distress. Therefore, it is reasonable to consider ICD deactivation if the patient or family wishes.

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A DIFFICULT DECISION

End-of-life decisions place significant emotional burdens on patients, their families, and their healthcare providers and can have social and legal consequences.

Turning off an ICD is an especially difficult decision, considering that these devices protect against sudden cardiac death and fatal arrhythmias. Also, patients and their representatives may find it more difficult to withdraw from active care than to forgo further interventions (more on this below), and they may misunderstand discussions about ICD deactivation, perceiving them as the beginning of abandonment.

ICD DEACTIVATION IS OFTEN DONE HAPHAZARDLY OR NOT AT ALL

Many healthcare providers are not trained in or comfortable with discussing end-of-life issues, and many hospitals and hospice programs lack policies and protocols for managing implanted devices at the end of life. Consequently, ICD management at the end of life varies among providers and tends to be suboptimal.[2]

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In a report of a survey in 414 hospice facilities, 97% of facilities reported that they admitted patients with ICDs, but only 10% had a policy on device deactivation.[3]

In a survey of 47 European medical centers, only 4% said they addressed ICD deactivation with their patients.[4]

A study of 125 patients with ICDs who had died found that 52% had do-not-resuscitate orders. Nevertheless, in 100 patients the ICD had remained active in the last 24 hours of their life, and 31 of these patients had received shocks during their last 24 hours.[5]

In a survey of next of kin of patients with ICDs who had died of any cause,[6] in only 27 of 100 cases had the clinician discussed ICD deactivation, and about three-fourths of these discussions had occurred during the last few days of life. Twenty-seven patients had received ICD discharges in the last month of life, and 8% had received a discharge during the final minutes.

TRAINING AND PROTOCOLS ARE NEEDED

Healthcare professionals need education about device deactivation at the end of life so that they are comfortable communicating with patients and families about this critical issue. To this end, several cardiac and palliative care societies have jointly released an expert statement on managing ICDs and other implantable devices in end-of-life situations.[7]

Many providers harbor a misunderstanding of the difference between *withholding* a device and *withdrawing* (or turning off) a device that is already implanted.[2] Some mistakenly believe they would be committing a crime by deactivating an implanted life-sustaining device. Legally and ethically, there is no difference between withholding a device and

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withdrawing a device. Legally, carrying out a request to withdraw life-sustaining treatment is neither physician-assisted suicide nor euthanasia.

DISCUSSION SHOULD BEGIN EARLY AND SHOULD BE ONGOING

The discussion of ICD deactivation should begin before the device is implanted and should continue as the patient's health status changes. In a survey, 40% of patients said they felt that ICD deactivation should be discussed before the device is implanted, and only 5% felt that this discussion should be undertaken in the last days of life.[8]

At the least, it is important to identify patients with ICDs on admission to hospice and to have policies in place that ensure adequate patient education to make an informed decision about ICD deactivation at the end of life.

The topic should be discussed when goals of care change and when do-not-resuscitate status is addressed, and also when advanced directives are being acknowledged. If the patient or his or her legal representative wishes to keep the ICD turned on, that wish should be respected. The essence of a discussion is not to impose the providers' choice on the patient, but to help the patient make the right decision for himself or herself. Of note, patients entering hospice do not have to have do-not-resuscitate status.

We believe that device management in end-of-life circumstances should be part of the discussion of the goals of care. Accordingly, healthcare providers need to be familiar with device management and to have a higher comfort level in addressing such sensitive topics with patients facing the end of life, as well as with their families.

It is also advisable to apply protocols within hospice services to address ICD management options for the patient and the legal representative. An early decision regarding end-of-life deactivation will help patients avoid distressing ICD discharges and the related emotional distress in their last moments.

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