## "Psychological quandaries," misunderstanding hamper doctor-patient talks on ICD deactivation

Oct 7, 2011 Steve Stiles

**New York, NY** - Guidance is out there, but how much is it heeded? The conversation between patients and providers on the possibility of implantable cardioverter defibrillator (ICD) deactivation near the end of life can be hobbled by misconceptions they have about each other, what the devices can achieve, and reluctance to even discuss the topic, suggests an analysis of the literature [1].

That's if the discussion even happens, according to **James E Russo** (Veterans Affairs Medical Center, New York, NY), coordinator of his center's pacemaker clinic and author of the literature review. In it, he points to data suggesting that most ICD recipients see their doctors as the primary source of information about their devices, yet most physicians don't see it as their responsibility to initiate discussion about device deactivation as part of end-of-life care.

They may avoid it or at least put it off because the prospect makes them uncomfortable, Russo notes, or they don't fully understand the device functions or feel qualified to raise the subject, or perhaps they aren't sure about the patient's prognosis.

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"Although patients don't often understand how their ICDs work and what their options are, physicians seem to believe that patients are knowledgeable about their ICDs. This misunderstanding may be another factor in delaying deactivation discussions, especially since many physicians say they'd prefer the patient or a family member to initiate the discussion. Yet, without physician prompting, a patient or family member might not do so until the patient is near death and perhaps already receiving shocks," he writes.

"Overall, the evidence suggests that providers consider discussing ICD deactivation only when a patient is terminally ill or actively dying, rather than well in advance of these states," Russo observes in the October 2011 American Journal of Nursing.

"It's a bit of a conundrum for providers," Russo told heartwire. "Primary-care providers may be the most likely to talk about advanced directives with patients but may not really know the full functionality of these devices and so may not have the expertise to speak to the patient and say these are the options."

He points to several publications with guidance for providers, including two that were published about the same time last year. One includes a detailed protocol for deactivating the shock function of ICDs and communicating with patients and their families [2]; the other is a consensus statement from the **Heart Rhythm Society**, the two major North American cardiology societies, and others [3].

The latter document, as **heartwire** reported on its release, details the often poorly understood rights of both patients and providers regarding device deactivation and the associated ethical, legal, and religious principles, a protocol for withdrawing device therapy, and the importance of clear communication between patients and providers. In particular, Russo notes, the statement provides sample questions providers can use to initiate a dialogue with patients.

Such recommendations are available, "but whether they are heeded is another story," he said. "It seems to me that when time is of the essence, that's when providers may start talking about it. Certainly there's a great deal of hesitance to start this discussion."



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One unusual aspect of Russo's review is its partial emphasis on the patient's point of view and its impact on any discussions with providers—something that's seldom been formally studied, he found. Those available were small and had significant limitations, he said.

They all suggested patients tend to prefer their devices to remain fully functional even at the end of life, "but did they really understand what that meant, to keep the device active? Did they know that the device could create a really painful experience for them if they had a terminal illness?" None of the findings were stratified by, for example, whether the patient had already experienced a shock; those who had would have been better prepared to realistically weigh their options, according to Russo.

Efforts to educate patients about their devices could face an obstacle not encountered with most other treatments. Some evidence suggests that patients with ICDs overestimate their ability to prevent death and, in fact, develop a "complex psychological relationship" with the device. They may have trouble grasping that a device designed to keep them alive could work to their disadvantage.

"I do see that patients tend to view these devices as kind of their guardian or protector. There's a bit of a psychological quandary for them that this thing that's supposed to protect them is also something that someone might recommend turning off," Russo said.

A possible hedge against such misunderstanding could be establishment of policies and guidelines at each institution for routinely discussing ICD deactivation with patients at the time of device implantation, something that only 4% cardiologists in one survey acknowledged they did, Russo reported.

Russo had no disclosures.

## Sources

- 1. Russo JE. Deactivation of ICDs at the end of life: a systematic review of clinical practices and provider and patient attitudes. *Am J Nurs* 2011; 111:26-35.
- 2. Goldstein N, Carlson M, Livote E, Kutner JS. Management of implantable cardioverter-defibrillators in hospice: A nationwide survey. *Ann Intern Med* 2010; 152:296-299. *20194235*
- 3. Lampert R, Hayes DL, Annas GJ, et al. HRS expert consensus statement on the management of cardiovascular implantable electronic devices (CIEDs) in patients nearing end of life or requesting withdrawal of therapy. *Heart Rhythm* 2010; 7:1008-1026.

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HRS issues guidance on tough device-withdrawal issues
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Most hospices ill-equipped to deal with ICDs
[Arrhythmia/EP > Arrhythmia/EP; Mar 04, 2010]
Team care approach helps patients consider ICD-shock withdrawal in end-of-life decisions
[Heart failure > Heart failure; Oct 03, 2006]
Choosing quality vs quantity of life in heart failure: Decisions often made early
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[Heart failure > Heart failure; Nov 14, 2006]

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